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Factors associated with patient activation in an Australian population with comorbid diabetes and chronic kidney disease

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Abstract

Objective To evaluate the extent of patient activation and factors associated with activation in adults with co-morbid diabetes and chronic kidney disease (CKD).

Design A cross sectional study.

Setting Renal/diabetes clinics of four tertiary hospitals in Australia.

Study population Adult patients with co-morbid diabetes and CKD (eGFR <60 mL/min/1.73m2).

Main outcome measures Patients completed the Patient Activation Measure, the Kidney Disease Quality of Life and demographic and clinical data survey. Factors associated with patient activation were examined using chi-squared or t-tests and linear regression.

Results 305 patients with median age of 68 (IQR 14.8) years were studied. They were evenly distributed across socioeconomic groups, stage of kidney disease and duration of diabetes but not gender. Approximately 46% reported low activation. In patients with low activation, the symptom/problem list, burden of kidney disease and mental composite subscales scores were all significantly lower (all $p<0.05$). On multivariable analysis, factors associated with lower activation for all patients were older age, worse self-reported health in the burden of kidney disease subscale and lower self-care scores. Additionally, in men, worse self-reported health in the mental composite subscale was associated with lower activation and in women worse self-reported health scores in the symptom problem list and greater renal impairment were associated with lower activation.

Conclusion Levels of activation are low in patients with diabetes and CKD. Older age and worse self-reported health were associated with lower activation. This data may serve as the basis for the development of interventions needed to enhance activation and outcomes for patients with diabetes and CKD.

Key words

Patient activation; diabetes; chronic kidney disease; self-care; health related quality of life

Strengths and limitations of this study

- Several biologic and non-biological patient variables were included as potential factors influencing patient activation since the factors are likely to be multifactorial.
- The study was conducted across multiple sites increasing the generalizability of the findings.
- The limitations include that our findings may not be generalised to culturally and linguistically diverse (CALD) populations.
- Cross sectional study design of the study did not permit us to assess temporal effects or to rule out the potential for reverse causality with low activation causing poor health.

INTRODUCTION

Patient activation may be defined as the ability and willingness of patients to take on the role of managing their own health and health care [1] and is related to the degree that a patient participates or engages in specific health behaviours. [2-4] Previous studies in hypertensive patients and adults attending primary care clinics suggest that patient activation is associated with patient outcomes with those individuals with low activation being more likely to smoke, [5] have a higher body mass index (BMI) and less likely to achieve cholesterol and glycated haemoglobin (HbA1c) targets. [6] In patients with diabetes, high activation has been associated with greater engagement in exercise, [7] fewer hospitalisations [8] and improved glycemic control. [9] In patients with hypertension [5, 10, 11] and chronic kidney disease (CKD), [12] high activation has been associated with better blood pressure control and in patients with end-stage kidney disease higher activation is likely to improve uptake of home dialysis. [13]

Low activation levels have been reported in 25-40% of the general population [14] and in patients living with chronic diseases. [12, 15, 16] However, activation levels may vary considerably depending on the severity of the chronic disease. [17, 18] Indeed, little is known about the activation levels of patients with multiple and complex chronic diseases, including co-morbid diabetes and CKD. Among patients with diabetes and CKD, a sufficient degree of activation is required for patients to perform self-management behaviors such as blood glucose monitoring and medication self-management. [19] Moreover, as these patients face competing treatment demands especially when treatment recommendations for one condition conflict with or impede management of the other, or when patients prioritize one condition over another, [20-22] understanding the degree of patient activation becomes even more important.

Missed opportunities to enhance activation among patients with diabetes and CKD may result in more rapid progression of CKD and development of associated complications. [23] Additionally, activation levels may fluctuate as the disease progresses and complications arise necessitating matched changes in activation behaviour. [24]

Given the importance of patient activation for self-management in people with diabetes and CKD and ultimately patient outcomes, it is important to establish the level of activation in these patients and determine the patient and disease characteristics that influence activation. Consequently, the purpose of the present study was to 1) examine the degree of activation of patients with co-morbid diabetes and CKD and 2) identify modifiable risk factors associated with activation levels in patients with co-morbid diabetes and CKD.

METHODS

Study design and participants

A cross-sectional study was conducted (as part of a larger health care improvement study) of patients attending diabetes and renal outpatient clinics of four public tertiary hospitals in Victoria and New South Wales (Monash Health, Alfred Health, Royal North Shore Hospital and Concord Hospital) between 2013 and December 2014. Participants were eligible if they received their usual care at these hospitals and had a diagnosis of diabetes (either type 1 or type 2) and chronic kidney disease stages 3 to 5 (eGFR<60 mL/min). The diagnosis of diabetes followed the World Health Organisation definition [25] and was recorded from patients' prior inpatient or outpatient contacts. Patients were recruited prospectively from clinics and asked to complete a number of questionnaires which included the Diabetes Renal Project Survey, the Patient Activation Measure (PAM-13) and the Kidney Disease Quality of

Life short form (KDQoL ™ -36) (Supplementary Appendices 1, 2 and 3). For each patient the site study staff or the clinician, using standardised procedures, also completed a corresponding clinical survey. All participants were provided with written informed consent and 317 agreed to participate. Monash University and the respective health service ethics committees approved the study.

Demographic and clinical variables

Age, gender, socio-economic status (SES), stage of kidney disease, duration of kidney disease and duration of diabetes were all recorded as possible determinants of patient activation. Socio-economic status was estimated using the Australian Bureau of Statistics data. [26] Postcodes were coded according to the Index of Relative Social Disadvantage (IRSD), a composite measure based on selected census variables, which include income, educational attainment and employment status. The IRSD scores for each postcode were then grouped into quintiles for analysis, where the highest quintile comprised 20% of postcodes with the highest IRSD scores (the most advantaged areas).

CKD stage as defined by the Kidney Disease: Improving Global Outcomes (KDIGO) was used to define severity of the disease. [27] Duration of CKD was analysed as a continuous variable. Estimated GFR was calculated using the CKD Epi formula. [28]

Health Related quality of life

Health related quality of life was assessed using the English version of the Kidney Disease and Quality of Life (KDQoL™-36) questionnaire, which is a 36-item HRQoL survey with five subscales, namely the SF-12 measure of physical and mental functioning, burden of kidney disease, symptom/problems list and the effects of kidney disease subscales. [29] Item scores were summed for each scale and transformed on a scale of 0 to 100 with a higher score

indicating better HRQoL. [28] The scores of the two summary measures and the total SF-36 are based on the average of the respective scale components.

Patient activation

A 13-item survey-based scale called the short form of the Patient Activation Measure (PAM-13) that groups patients along a four-point levelling scale based on how activated patients are was used to measure patient activation. It has similar reliability and validity to the 22-item version across different ages, genders and health condition status. [30] Each item of the form was scored on the 5-point Likert response scale. The raw scores were transformed from the original metric to a 0–100 metric with higher scores indicating higher activation levels. Patients were categorized into four levels: level 1 (score <47.0), level 2 (score 47.1–55.1), level 3 (score 55.2–67.0), and level 4 (score >67.0 based on the predefined categorisation of activation scores according to Hibbard and others. [30] The activation levels were then dichotomized into low activation (Levels 1 and 2) and high activation (Levels 3 and 4) as reported in previous studies. [31, 32]

Data analysis

Normally distributed data are presented with mean and standard deviation (SD) as the measures of central tendency and dispersion, respectively. Correspondingly, non-normally distributed continuous data are presented with median and interquartile range (IQR, thus 25th and 75th percentiles), respectively. All HRQoL subscales were treated as continuous variables. First, the four patient activation levels were dichotomized into low activation group (Levels 1 and 2) and high activation group (Levels 3 and 4). Second, chi-squared or t-tests (as appropriate) were used to analyse differences or associations between patient and disease characteristics and patient activation. Third, using the PAM score as a continuous variable,

univariable regression models were performed in which each covariate was controlled for separately to ascertain its potential importance. Covariates that reached a significance level of $p<0.10$ or were of clinical importance were included in stepwise backward multivariable linear regression models that investigated the factors associated with patient activation for the entire study population and stratified analyses according to gender [33]. Confidence intervals (CIs) were reported at the 95% level and results were considered significant at conventional $p<0.05$ level. All analyses were performed with IBM SPSS version 22 (Armonk, NY: IBM Corp.) or Stata version 12.1 (Statacorp, College Station, TX).

RESULTS

Patient characteristics

The baseline demographic and clinical characteristics of the study population are shown in Table 1. A total of 305 patients (30% women) were included in the analyses after exclusion of 9 patients who had their eGFR misclassified (>60ml/min/m^2) and 3 patients who had incomplete PAM data. The median age and interquartile range (IQR) was 68 and 14.8 years respectively with 59% of the population being over 68 years old. The patients were evenly distributed across groups defined by SES and stage of kidney disease. Approximately 20% were receiving dialysis treatment.

Patient activation scores were normally distributed across the study population (mean 57.6, SD 15.5); men (mean 57.4, SD 16.0) and women patients (mean 58.1, SD 14.4) (Figure 1). The proportions of the patients with low (levels 1 and 2) and high activation (levels 3 and 4) scores were 46% and 54% respectively (Figure 1).

Patients in the low activation group had significantly worse self-reported health in the burden of kidney disease and mental composite summary subscales than patients in the high activation group (all $p<0.05$). No other differences between low and high activation groups were found for demographic factors (age, gender and socioeconomic status) and disease factors that included stage and duration of CKD, dialysis status, duration of diabetes and BMI (Table 1).

Factors associated with patient activation in the study population

On univariable analysis (Table 2), factors associated with lower activation were worse self-reported health in all HRQOL subscales, greater renal impairment (lower eGFR) and lower self-care scores. On multivariable analysis, older age, worse self-reported health in the burden of kidney disease subscale and lower self-care scores were independently associated with lower activation (Table 2).

Factors associated with patient activation stratified by gender

Tables S1 and S2 show stratified analyses according to gender. On univariable analysis, worse self-reported health in the symptom problems list, burden of kidney disease, mental composite summary subscales and lower self-care scores were associated with lower activation in men and worse self-reported health in all HRQOL subscales and lower eGFR were associated with lower activation in women. On multivariable analysis, worse self-reported health in the mental composite subscale was independently associated with lower activation in men, and worse self-reported health in the symptom problem list and greater renal impairment (lower eGFR) were independently associated with lower activation in women.

DISCUSSION

Amongst patients with co-morbid diabetes and CKD, we document for the first time in this study that patient activation is low, and identify factors independently associated with lower patient activation. We report significantly worse self-reported health in the burden of kidney disease and mental composite subscales for patients in the low activation group compared to those in the high activation group. Lower activation was also independently associated with older age, having worse self-reported health in the burden of kidney disease subscale and lower self-care scores across the entire study population. In men, worse self-reported health in the mental composite subscale was associated with lower activation, and in women worse self-reported health in the symptom problem list and greater renal impairment were associated with lower patient activation.

Patient activation in patients with co-morbid diabetes and CKD was generally low with close to 50% of our study population reporting low levels of activation. This is greater than that of the general population where 25 to 40% have reported low activation [14] and in patients with diabetes where 20 to 30% reported low activation. [33, 34] Conversely in patients with CKD alone (eGFR<60 mL/min/1.73m^2), patient activation has been observed to be even lower with over 65% of one study cohort [17] reporting low activation levels. The attenuating effect of diabetes on patient activation in patients with CKD may be related to the focus on patient self-management in diabetes fostering greater patient activation. This suggests the tenet of diabetes management being patient self-management may foster greater patient activation. More studies are required to confirm this observation.

We found that older age was independently associated with lower activation. Similar findings have been reported in people with diabetes [8, 16, 26] other chronic diseases [32, 35-38] and in a national survey of US adults. [39] In contrast, other studies in different populations found

conflicting evidence, showing no direct relationship between patient activation and age. [2, 40-42] These inconsistencies may be due to differences in clinical and demographic characteristics of the populations studied. For example, it has been previously reported that younger patients with CKD have poor coping strategies compared to older patients [43] and this may potentially lead to low activation. Our results highlight a subgroup at risk of lower activation, which may benefit from targeted interventions to improve activation. Additionally, the contradictions regarding the relationship between age and patient activation highlight that intervention strategies cannot exclusively be based on the knowledge of patients' demographics, but should include other modifiable factors as well.

In line with previous studies of patients with conditions other than co-morbid diabetes and CKD, [15, 36, 39, 44-46] patient activation was low in those with worse self-reported health status. Our study showed that lower mental health composite scores on KDQoL were independently associated with lower patient activation, particularly in men. This could be due to men with co-morbid disease having less ability to cope with multiple conditions than women, [47] resulting in lower levels of activation. Given the high prevalence of mental disorders such as depression in patients with CKD, [48] addressing mental health issues may be very important for enhancing patient activation and outcomes.

Our data suggest that greater renal impairment in women may be associated with lower activation. The most likely explanation for this is that women tend to have lower physical functioning [49, 50] even in early stages of CKD which is associated with low patient activation. [17, 39] Another plausible explanation is that women may receive less support from their care givers compared to men due to caregiver stress and fatigue [51] associated with managing chronic diseases leading to lower activation.

Interestingly, we did not find a significant association between SES and patient activation. This is in contrast to other studies that have reported patient activation to vary by SES with individuals from lower SES groups reported as less activated than those from higher SES groups. [6, 14] These discordant findings could be attributable to our use of postcode as a surrogate for SES, which may not accurately represent SES.

Strengths and limitations

Our findings should be interpreted in light of the strengths and limitations of our study design. The strengths include the inclusion of several biologic and non-biological patient variables as potential factors influencing patient activation since the factors are likely to be multifactorial. The study was conducted across multiple sites increasing the generalizability of the findings [52] and we also used validated and disease-specific instruments for measuring HRQoL (KDQoL™-36) and patient activation (PAM 13™). The limitations include that our findings may not be generalised to culturally and linguistically diverse (CALD) populations. The cross sectional design of the study also did not permit us to assess temporal effects or to rule out the potential for reverse causality with low activation causing poor health. Longitudinal studies would need to be conducted to better understand the effects over time of factors influencing patient activation in this population.

Conclusions

In conclusion, in patients with co-morbid diabetes and CKD patient activation was low, with almost half of patients reporting low activation. Older age and worse self-reported health were associated with lower activation. This data may serve as the basis for the development of interventions needed to enhance activation and outcomes for patients with diabetes and CKD.

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Contributors

EZ, CL and SZ conceptualised the study. EZ, CL, SR and SZ performed data curation. EZ designed the analysis in consultation with CL, SR, GF, SJ, PK, KP, GR, RW, and SZ. EZ drafted the original draft and all authors reviewed and edited the final manuscript.

Conflicts of Interest

The authors declare no conflicts of interest in relation to this work.

Ethics approval

Approval for the Diabetes Renal Project (DRP) was obtained from Monash University, Monash Health, Alfred Health, Royal North Shore Hospital and Concord Hospital.

Data sharing statement

Data for the DRP study can be shared for specific research questions that are available from the corresponding author on request.

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Table 1: Patient characteristics by activation status (N=305)

	Patient activation status		*p*-value[1]
	Low level N (%)	High level N (%)	
Age			
<68 years	68 (49.3)	88 (53.3)	0.48
≥68 years	70 (50.7)	77 (46.7)	
Gender			
Women	42 (30.4)	51 (30.9)	0.93
Men	96 (69.6)	114 (69.1)	
Socio-economic status, n: (%)			0.86
Upper	24 (17.4)	34 (20.6)	
Upper middle	32 (23.2)	31 (18.8)	
Lower middle	27 (19.6)	34 (20.6)	
Upper lower	28 (20.3)	31 (18.8)	
Lower	27 (19.6)	35 (21.2)	
CKD[2] duration in years: mean (SD)	8.8 (9.6)	9.2 (11.6)	0.74
Stage of CKD			0.86
3a	30 (21.7)	42 (25.5)	
3b	35 (25.4)	42 (25.5)	
4	34 (24.6)	40 (24.2)	
5	39 (28.3)	41 (24.8)	
Diabetes duration in years: mean (SD)	17.1 (12.0)	18.2 (11.8)	0.40
Body mass index: mean, n: (%)			
Underweight	1 (1.4)	1 (1.2)	0.60
Health weight	17 (24.3)	15 (17.4)	
Overweight	21 (30.0)	23 (26.7)	
Obese	47 (67.1)	31 (36.0)	
Dialysis status			
Current	29 (21.0)	30 (18.2)	0.54
Predialysis	109 (79.0)	135 (81.8)	
HRQOL[3]: mean (SD)			
Symptom/problem list	72.0 (17.6)	75.5 (17.4)	0.08
Effect of kidney disease	71.0 (23.5)	74.1 (23.6)	0.27
Burden of kidney disease	55.9 (29.5)	63.3 (31.9)	0.04
Physical composite summary	34.4 (11.3)	36.0 (11.0)	0.26
Mental composite summary	45.5 (10.5)	48.3 (11.0)	0.03

Data are presented in N (%) unless otherwise indicated.

[1] T-test for mean differences and chi-square test for differences in proportions; [2] chronic kidney disease; [3] Health related quality of life

Table 2: Univariable and multivariable regression model for factors associated with activation in the study population

Variables	Univariable B (95% CI)	Multivariable B (95% CI)
Age	-0.05 (-0.22 to 0.11)	-0.18 (-0.35 to -0.01)*
Gender		
Men	Ref	Ref
Women	-0.79 (-4.59 to 3.02)	-
Health related quality of life		
Symptom problem list	0.15 (0.05 to 0.25)**	-
Effects of kidney disease	0.09 (0.02 to 0.17)*	-
Burden of kidney disease	0.11 (0.05 to 0.16)***	0.11 (0.05 to 0.17)***
Physical composite summary	0.17 (0.01 to 0.33)*	-
Mental composite summary	0.26 (0.09 to 0.42)**	-
Duration of diabetes	-0.02 (-0.17 to 0.13)	-
Duration of kidney disease	0.07 (-0.11 to 0.25)	-
eGFR [a]	0.11 (0.00 to 0.21)*	0.01 (-0.12 to 0.15)
Body mass index		
Health weight [b]	Ref	Ref
Overweight	-2.78 (-7.75 to 2.20)	-
Obese	1.98)-2.03 to 5.99)	-
Socioeconomic status		
Lower	Ref	Ref
Lower middle	-0.31 (-4.75 to 4.12)	-
Upper lower	-1.42 (-5.80 to 2.95)	-
Upper middle	-0.95 (-5.27 to 3.38))	-
Upper	3.17 (-1.28 7.62)	-
Self-care composite score	0.21 (0.06 to 0.37)**	0.18 (0.02 to 0.35)*

*p<0.05; **p<0.01, ***p<0.001; a-per 1ml/min increase in eGFR; b-due to small numbers of underweight patients (N=2), the underweight group was combined with the health weight group for this analysis.

S1: Univariable and multivariable regression model for factors associated with activation in men with diabetes and chronic kidney disease

Variables	Univariable B (95% CI)	Multivariable B (95% CI)
Age	-0.11 (-0.32 to 0.12)	-
Health related quality of life		
Symptom problem list	0.12 (0.04 to 0.25)*	-
Effects of kidney disease	0.04 (-0.05 to 0.13)	-
Burden of kidney disease	0.08 (0.01 to 0.15)*	-
Physical composite summary	0.06 (-0.15 to 0.26)	-
Mental composite summary	0.23 (0.03 to 0.43)*	0.23 (0.02 to 0.44)*
Duration of diabetes	0.01 (-0.17 to 0.20)	-
Duration of kidney disease	0.10 (-0.12 to 0.16)	-
eGFR	0.03 (-0.12 to 0.16)	-
Body mass index		
Health weight [a]	Ref	Ref
Overweight	-5.08 (-10.96 to 0.80)	-
Obese	2.87 (-2.08 to 7.81)	-
Socioeconomic status		
Lower	Ref	Ref
Lower middle	0.41 (-5.04 to 5.85)	-
Upper lower	-0.63 (-5.98 to 4.73)	-
Upper middle	-2.23 (-7.37 to 2.92)	-
Upper	4.65 (-1.04 to 10.33)*	-

*p<0.05; **p<0.01, ***p<0.001; a-due to small numbers of underweight patients (N=2), the underweight group was combined with the health weight group for this analysis

S2: Univariable and multivariable regression model for factors associated with activation in women with diabetes and chronic kidney disease

Variables	Univariable B (95% CI)	Multivariable B (95% CI)
Age	0.02 (-0.21 to 0.26)	-
Health related quality of life		
Symptom problem list	0.21 (0.06 to 0.36)**	0.2 (0.05 to 0.35)**
Effects of kidney disease	0.21 (0.09 to 0.33)**	-
Burden of kidney disease	0.18 (0.09 to 0.27)***	-
Physical composite summary	0.45 (0.19 to 0.71)**	-
Mental composite summary	0.33 (0.05 to 0.60)*	-
Duration of diabetes	-0.09 (-0.35 to 0.17)	-
Duration of kidney disease	0.02 (-0.31 to 0.27)	-
eGFR	0.27 (0.10 to 0.43)**	0.27 (0.11 to 0.44)**
Body mass index		
Health weight	Ref	Ref
Overweight	4.85 (-4.75 to 14.40)	-
Obese	-0.66 (-7.00 to 6.87)	-
Socioeconomic status		
Lower	Ref	Ref
Lower middle	-1.99 (-9.71 to 5.73)	-
Upper lower	-3.33 (-11.03 to 4.38)	-
Upper middle	-3.40 (-4.93 to 11.73)	-
Upper	0.27 (-6.88 to 7.42)	-
Self-care composite score	0.23 (-0.06 to 0.53	-

*p<0.05; **p<0.01, ***p<0.001

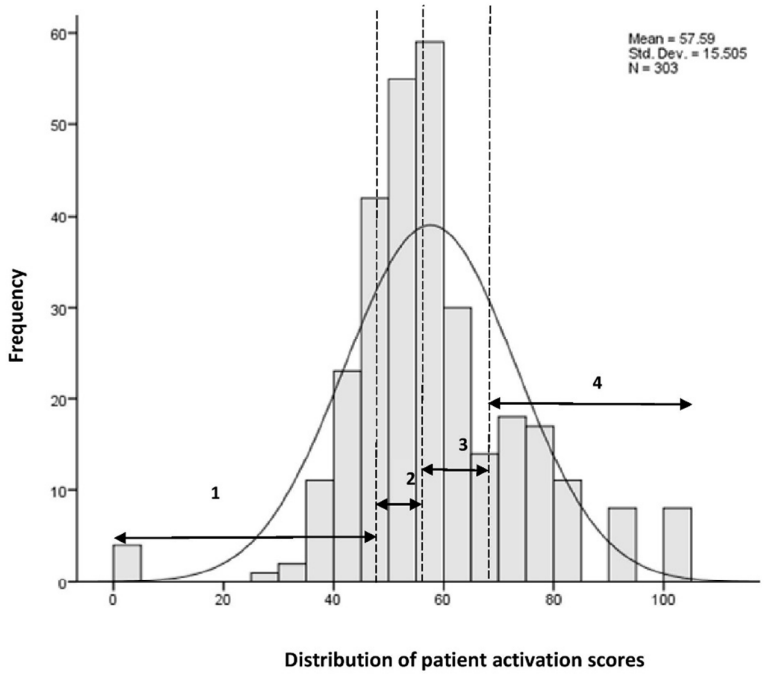

Figure 1: Distribution of participants across the four levels of patient activation. Level 1 (score of 0.0–47.0) indicates that a person may not yet understand that their role as a patient is important. Level 2 (47.1– 55.1) indicates that a person lacks the confidence and knowledge to take action. Level 3 (55.2– 67) indicates that a person is beginning to take action and level 4 (67.1–100) indicates that a person is proactive about health and engages in many recommended health behaviors

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Hospital ID: Site Staff ID: Participant ID:

DRP: Diabetes Renal Project (Doctors Survey - Health Indicators)

Thank-you for participating in this large multi-centre research project, called the Diabetes Renal Project (DRP). This National Health and Medical Research Council (NHMRC) partnership project is being conducted by Monash University, in partnership with Monash Health, Alfred Health, Royal North Shore Hospital, Concord Repatriation General Hospital, The George Institute for Global Health, Diabetes Australia, and Kidney Health Australia.

INSTRUCTIONS

PLEASE:
Use a black **BIRO**, (DO NOT use a pencil or a fountain or felt tip pen)

Please **PRINT** in **CAPITAL** letters and stay within the box provided for text.

If you make a **mistake when writing**, cross it out with one thick line and write your correct answer above the box.

To answer a multiple choice question place a **CROSS INSIDE** the box like this: X

If you make a **mistake**, place a diagonal line through the incorrect answer like this: X and then put a cross in the box of your preferred response.

Write dates using leading zeros (e.g. **6th April 2011 = 06/04/2011**)

DO NOT USE liquid paper to correct mistakes.

AVOID folding the form.

Please complete every page of the questionnaire. Sometimes questions may seem very similar or repetitious but they are all a little different, so please answer each question.

THANK YOU

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Hospital ID: Site Staff ID: Participant ID:

Date day / month / year

Health Indicators (Doctors Survey)

Section 1: Demographic of Patient Participant

1. Age *(years)*

2. Gender ☐ Male ☐ Female

3. Participant Post-code

4. Aboriginal background ☐ No ☐ Yes

5.Torres Strait Islander background ☐ No ☐ Yes

6. Maori/Pacific Strait Islander background ☐ No ☐ Yes

7. Is the participant a current smoker ?

☐ No → Skip to Q 8

☐ Yes → **7.1. Average number of cigarettes smoked per day?**

8. Has the participant previously smoked ?

☐ No → Skip to Q 9

☐ Yes → **8.1. Average number of cigarettes smoked per day?**

9. Does the participant currently drink alcohol?

☐ No → Skip to Q 10

☐ Yes → **9.1. Average number of standard drinks per week?**

Section 2: Examination Findings

Please complete with the most recent examination findings and date of examination

10. Blood Pressure - *(the average of 3 readings measured after 5 minutes sitting)*

/ mmHg → **10.1** day / month / year

11. Heart Rate Bpm → **11.1** day / month / year

12. Weight . Kg → **12.1** day / month / year

13. Height . Metres → **13.1** day / month / year

At the most recent examination, does the participant have the following conditions:

14a. New loss of vibratory sensation (both feet)

☐ No ☐ Yes → Date of examination **14a.1** day / month / year

☐ Not examined/unknown

14b. New loss of ankle reflexes (both legs)

☐ No ☐ Yes → Date of examination **14b.1** day / month / year

☐ Not examined/unknown

14c. New loss of light touch (eg. loss of pressure sensation with 10gm force monofilament)

☐ No ☐ Yes → Date of examination **14c.1** day / month / year

☐ Not examined/unknown

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Hospital ID: Site Staff ID: Participant ID:

Section 2: Examination Findings (cont)

15. Foot ulcers

☐ No ☐ Yes → Date of examination **15.1** day / month / year

☐ Not examined/unknown

16. Foot deformity

☐ No ☐ Yes → Date of examination **16.1** day / month / year

☐ Not examined/unknown

Section 3: Medical History

17. Diabetes Type ☐ Type 1 ☐ Type 2 **18. Duration of diabetes** *years* *months*

OR ☐ Unknown/not documented

Has the participant experienced any of the following complications/comorbidities?

19. Ischemic Heart Disease?	☐ No	☐ Yes	**23. Peripheral Neuropathy?**	☐ No	☐ Yes
20. Stroke?	☐ No	☐ Yes	**24. Diabetic Nephropathy?**	☐ No	☐ Yes
21. Peripheral Vascular disease?	☐ No	☐ Yes	**25. Hypertension**	☐ No	☐ Yes
22. Diabetic Retinopathy?	☐ No	☐ Yes	**26. Dyslipidemia**	☐ No	☐ Yes

27. Does the participant have a family history of heart disease? ☐ No ☐ Yes

OR ☐ Unknown/not documented

---

28. Duration of nephrological care *years* *months* **OR** ☐ Unknown/not documented

29. Kidney disease stage *(select one option)* ☐ Stage 3a ☐ Stage 3b ☐ Stage 4 ☐ Stage 5

30. Is the patient currently on dialysis?

☐ No → Skip to Q 31

☐ Yes → **30.1 Haemodialysis** ☐ No ☐ Yes → **30.2** Number of months on dialysis

30.3 Peritoneal ☐ No ☐ Yes → **30.4** Number of months on dialysis

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Hospital ID: Site Staff ID: Participant ID:

Section 3: Medical History (cont)

31. Prior to their current dialysis, has the patient been on any other form of dialysis?

☐ No → Skip to Q 32

☐ Yes→ **31.1 Haemodialysis?** ☐ No ☐ Yes

Date commenced **31.2** ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year)

Date ceased **31.3** ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year)

31.4 Peritoneal dialysis? ☐ No ☐ Yes

Date commenced **31.5** ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year)

Date ceased **31.6** ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year)

32. Has the patient had a kidney transplant?

☐ No → Skip to Q 33

☐ Yes→ **32.1 Date of transplant** ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year)

OR ☐ Unknown/not documented

Section 4: Medical Care of Diabetes and Chronic Kidney Disease

33. How often does the participant monitor his/her diabetes with a blood glucose monitor? *(select one option)*

☐ ≥ 3 times per day ☐ Once per day (daily) ☐ Once per week (weekly) ☐ Uncertain

☐ 2 times per day ☐ A few times per week ☐ Rarely ☐ Not documented

34. Please indicate when the participant was last referred/seen by the following health professionals. *(Select the appropriate response for each health professional).*

	Not referred/reviewed by this health professional	3 months or less	4-12 months ago	13-24 months ago	As required	Uncertain
a. Endocrinologist	☐	☐	☐	☐	☐	☐
b. Nephrologist	☐	☐	☐	☐	☐	☐
c. Diabetes Nurse Educator	☐	☐	☐	☐	☐	☐
d. Renal Nurse Practitioner	☐	☐	☐	☐	☐	☐
e. Optometrist	☐	☐	☐	☐	☐	☐
f. Ophthalmologist	☐	☐	☐	☐	☐	☐
g. Podiatrist	☐	☐	☐	☐	☐	☐
h. Dentist	☐	☐	☐	☐	☐	☐
i. Dietician	☐	☐	☐	☐	☐	☐
j. Social Worker	☐	☐	☐	☐	☐	☐

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Hospital ID: Site Staff ID: Participant ID:

Section 5: Medications

35. Is the participant on Insulin?

☐ No → Skip to Q 36

☐ Yes→ **35.1 Is the participant on an Insulin pump?** ☐ No ☐ Yes

35.2 What type of insulin? *(select all that apply)*

☐ Long acting ☐ Short acting ☐ Rapid acting ☐ Basal

36. Is the participant on diabetes tablets?

☐ No → Skip to Q 34

☐ Yes→ **Does the participant take:**

36.1 Metformin?	☐ No	☐ Yes
36.2 Sulphonylurea?	☐ No	☐ Yes
36.3 Glitazone?	☐ No	☐ Yes
36.4 Acarbose?	☐ No	☐ Yes
36.5 Gliptin (DPP4 inhibitor)?	☐ No	☐ Yes
36.6 GLP1 agonist? (e.g exenatide or liraglutide)	☐ No	☐ Yes
36.7 SGLT2 inhibitors?	☐ No	☐ Yes

36.8 Other diabetes medication *(please list below)*

37. Other medications - is the participant taking:

37.1 ACE inhibitor?	☐ No	☐ Yes
37.2 Angiotensin2 Receptor Blocker?	☐ No	☐ Yes
37.3 Other Antihypertensives?	☐ No	☐ Yes
37.4 Statin?	☐ No	☐ Yes
37.5Fibrate?	☐ No	☐ Yes
37.6 Erythropoieting Stimulating Agent?	☐ No	☐ Yes
37.7 Phosphate binder?	☐ No	☐ Yes
37.8 Iron Supplementation (IV or Oral)?	☐ No	☐ Yes

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Hospital ID: ☐ Site Staff ID: ☐☐☐☐☐ Participant ID: ☐☐☐☐

Section 6: Investigations

38. Has a HbA1c test been performed in the last 3 months? ☐ No ☐ Yes

Please record the most recent HbA1c result

38.1 HbA1c ☐☐☐ mmol/mol ***and*** **38.2** ☐☐.☐ % → **38.3** Date of test ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year)

39. Please enter details below of the most recent lipid profile results:

39.1 Total Cholesterol ☐☐.☐ mmol/L

39.2 LDL Cholesterol ☐.☐☐ mmol/L

39.3 HDL Cholesterol ☐☐.☐☐ mmol/L

39.4 Triglycerides ☐.☐☐ mmol/L

39.5 Date of test ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year)

OR ☐ Not tested

40. Please enter details below of the most recent serum biochemistry profile results:

40.1 Potassium ☐.☐ mmol/L

40.2 Creatinine ☐☐☐☐ µmol/L

40.3 Calcium ☐.☐☐ mmol/L

40.4 Phosphate ☐.☐☐ mmol/L

40.5 Parathyroid hormone (PTH) ☐☐☐.☐
(result within last 6 months)

40.5.1 Units ☐ pmol/L ☐ ng/L

OR ☐ Not done within the past 6 months

40.6 eGFR ☐☐☐ mL/min per 1.73m^2

40.7 Albumin ☐☐☐ g/L

40.8 Date of test ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year)

(For PTH, please record result from within the past 6 months of this date)

OR ☐ Not tested

41. Please record the most recent spot urine albumin / creatinine ratio (ACR):

☐☐☐☐.☐☐ mg/mmol **40.1 Date of test** ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year) **OR** ☐ Not tested

42. If you have used another method to measure microalbumin / proteinuria please record details below:

☐☐☐☐.☐☐ **42.1 Units** ☐ mg/L ☐ mg/24hr ☐ µg/min ☐ g/mmol ☐ g/L

42.2 Date of test ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year) **OR** ☐ Not tested

43. Please enter the most recent Haemoglobin test result: ☐☐☐ g/L **43.1 Date of test** ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year)

OR ☐ Not tested

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Hospital ID: Site Staff ID: Participant ID:

Date ___ / ___ / ____ (day / month / year)

Patient Activation Measure (PAM) 13™ ©Insignia Health, LLC 2013

Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by crossing your answer. Your answers should be what is true for you and not just what you think others want you to say. If the statement does not apply to you, cross N/A. (Please choose only one response for each statement).

	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
1. When all is said and done, I am the person who is responsible for taking care of my health	☐	☐	☐	☐	☐
2. Taking an active role in my own health care is the most important thing that affects my health	☐	☐	☐	☐	☐
3. I am confident that I can help prevent or reduce problems associated with my health	☐	☐	☐	☐	☐
4. I know what each of my prescribed medications do	☐	☐	☐	☐	☐
5. I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself	☐	☐	☐	☐	☐
6. I am confident that I can tell a doctor concerns I have even when he or she does not ask	☐	☐	☐	☐	☐
7. I am confident that I can follow through on medical treatments I may need to do at home	☐	☐	☐	☐	☐
8. I understand my health problems and what causes them	☐	☐	☐	☐	☐
9. I know what treatments are available for my health problems	☐	☐	☐	☐	☐
10. I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising	☐	☐	☐	☐	☐
11. I know how to prevent problems with my health	☐	☐	☐	☐	☐
12. I am confident I can figure out solutions when new problems arise with my health	☐	☐	☐	☐	☐
13. I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress	☐	☐	☐	☐	☐

Your Health

– *and* –

Well-Being

Kidney Disease and Quality of Life (KDQOL™-36)

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Thank you for completing these questions!

Study of Quality of Life For Patients on Dialysis

What is the purpose of the study?

This study is being carried out in cooperation with physicians and their patients. The purpose is to assess the quality of life of patients with kidney disease.

What will I be asked to do?

For this study, we want you to complete a survey today about your health, how you feel and your background.

Confidentiality of information?

We do not ask for your name. Your answers will be combined with those of other participants in reporting the findings of the study. Any information that would permit identification of you will be regarded as strictly confidential. In addition, all information collected will be used only for purposes of the study, and will not be disclosed or released for any other purpose without your prior consent.

How will participation benefit me?

The information you provide will tell us how you feel about your care and further understanding about the effects of medical care on the health of patients. This information will help to evaluate the care delivered.

Do I have to take part?

You do not have to fill out the survey and you can refuse to answer any question. Your decision to participate will not affect your opportunity to receive care.

Your Health

This survey includes a wide variety of questions about your health and your life. We are interested in how you feel about each of these issues.

1. In general, would you say your health is: [Mark an ☒ in the one box that best describes your answer.]

Excellent	Very good	Good	Fair	Poor
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? [Mark an ☒ in a box on each line.]

	Yes, limited a lot	Yes, limited a little	No, not limited at all
2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	☐ 1	☐ 2	☐ 3
3. Climbing several flights of stairs	☐ 1	☐ 2	☐ 3

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	Yes	No
4. Accomplished less than you would like.....	☐ 1	☐ 2
5. Were limited in the kind of work or other activities	☐ 1	☐ 2

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	Yes	No
6. Accomplished less than you would like.....	☐ 1	☐ 2
7. Didn't do work or other activities as carefully as usual	☐ 1	☐ 2

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks…

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
9. Have you felt calm and peaceful?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
10. Did you have a lot of energy?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
11. Have you felt downhearted and blue?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

12. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Your Kidney Disease

How true or false is each of the following statements for you?

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
13. My kidney disease interferes too much with my life	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
14. Too much of my time is spent dealing with my kidney disease	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
15. I feel frustrated dealing with my kidney disease	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
16. I feel like a burden on my family	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

During the <u>past 4 weeks</u>, to what extent were you bothered by each of the following?

	Not at all bothered	Somewhat bothered	Moderately bothered	Very much bothered	Extremely bothered
	▼	▼	▼	▼	▼
17. Soreness in your muscles?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
18. Chest pain?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
19. Cramps?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
20. Itchy skin?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
21. Dry skin?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
22. Shortness of breath?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
23. Faintness or dizziness?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
24. Lack of appetite?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
25. Washed out or drained?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
26. Numbness in hands or feet?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
27. Nausea or upset stomach?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
28[a]. (Hemodialysis patient only) Problems with your access site?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
28[b]. (Peritoneal dialysis patient only) Problems with your catheter site?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Effects of Kidney Disease on Your Daily Life

Some people are bothered by the effects of kidney disease on their daily life, while others are not. How much does kidney disease <u>bother</u> you in each of the following areas?

	Not at all bothered	Somewhat bothered	Moderately bothered	Very much bothered	Extremely bothered
29. Fluid restriction?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
30. Dietary restriction?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
31. Your ability to work around the house?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
32. Your ability to travel?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
33. Being dependent on doctors and other medical staff?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
34. Stress or worries caused by kidney disease?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
35. Your sex life?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
36. Your personal appearance?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Thank you for completing these questions!

STROBE Statement—Checklist of items that should be included in reports of ***cross-sectional studies***

	Item No	Recommendation
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract (Page 2 and page 5)
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found (Page 2-abstract)
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported (Page 4 to 5 of the background)
Objectives	3	State specific objectives, including any prespecified hypotheses (Stated on page 5, second paragraph)
Methods		
Study design	4	Present key elements of study design early in the paper (Page 5, under methods)
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection (Page 5, under methods)
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants (Page 5, lines 18-24)
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable (Page 6 to 7)
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group (Page 6 and 7; health related quality of life and patient activation)
Bias	9	Describe any efforts to address potential sources of bias (Page 6 and 7, validated measures were used)
Study size	10	Explain how the study size was arrived at
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why (Page 7 under data analysis)
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding (Page 7 to 8)
		(*b*) Describe any methods used to examine subgroups and interactions (Page 8, lines 1 to 4)
		(*c*) Explain how missing data were addressed (Page 8, line 13-15)
		(*d*) If applicable, describe analytical methods taking account of sampling strategy (N/A)
		(*e*) Describe any sensitivity analyses
Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (Page 8, line 13)
		(b) Give reasons for non-participation at each stage
		(c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (Page 8, line 15 to 22)
		(b) Indicate number of participants with missing data for each variable of interest (Page 8, line 15 to 16)

Outcome data	15*	Report numbers of outcome events or summary measures
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (Page 9)
		(*b*) Report category boundaries when continuous variables were categorized
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period N/A
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses (Page 9, lines 14 to 22- subgroup analyses by gender)
Discussion		
Key results	18	Summarise key results with reference to study objectives (Page 10, lines 1 to 10)
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias (Page 12, lines page 12 to 16)
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence (page 10 to 11)
Generalisability	21	Discuss the generalisability (external validity) of the study results (Page 12, lines 9 to 12)
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based (Page 19, under funding)

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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Factors associated with patient activation in an Australian population with comorbid diabetes and chronic kidney disease: a cross sectional study

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Factors associated with patient activation in an Australian population with comorbid diabetes and chronic kidney disease: a cross sectional study

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Abstract

Objective To evaluate the extent of patient activation and factors associated with activation in adults with co-morbid diabetes and chronic kidney disease (CKD).

Design A cross sectional study.

Setting Renal/diabetes clinics of four tertiary hospitals across the 2 largest states of Australia.

Study population Adult patients (over 18 years) with co-morbid diabetes and CKD (eGFR <60 mL/min/1.73m^2).

Main outcome measures Patients completed the Patient Activation Measure, the Kidney Disease Quality of Life and demographic and clinical data survey from January to December 2014. Factors associated with patient activation were examined using chi-squared or t-tests and linear regression.

Results Three hundred and five patients with median age of 68 (IQR 14.8) years were studied. They were evenly distributed across socioeconomic groups, stage of kidney disease and duration of diabetes but not gender. Approximately 46% reported low activation. In patients with low activation, the symptom/problem list, burden of kidney disease and mental composite subscales scores were all significantly lower (all p<0.05). On multivariable analysis, factors associated with lower activation for all patients were older age, worse self-reported health in the burden of kidney disease subscale and lower self-care scores. Additionally, in men, worse self-reported health in the mental composite subscale was associated with lower activation and in women, worse self-reported health scores in the symptom problem list and greater renal impairment were associated with lower activation.

Conclusion Findings from this study suggest that levels of activation are low in patients with diabetes and CKD. Older age and worse self-reported health were associated with lower activation. This data may serve as the basis for the development of interventions needed to enhance activation and outcomes for patients with diabetes and CKD.

Key words

Patient activation; diabetes; chronic kidney disease; self-care; health related quality of life

Strengths and limitations of this study

- Several biologic and non-biological patient variables were included as potential factors influencing patient activation since the factors are likely to be multifactorial.
- The study was conducted across multiple sites increasing the generalizability of the findings.
- The limitations include that our findings may not be generalised to culturally and linguistically diverse (CALD) populations.
- Cross sectional study design of the study did not permit us to assess temporal effects or to rule out the potential for reverse causality with low activation causing poor health.

INTRODUCTION

Patient activation may be defined as the ability and willingness of patients to take on the role of managing their own health and health care [1] and is related to the degree that a patient participates or engages in specific health behaviours. [2-4] Previous studies of hypertensive patients in primary care settings suggest that patient activation is associated with patient outcomes, where low activated patients are more likely to smoke, [5] have a higher body mass index (BMI) and less likely to achieve cholesterol and glycated haemoglobin (HbA1c) targets. [6] In patients with diabetes, high activation has been associated with greater engagement in exercise, [7] fewer hospitalisations [8] and improved glycemic control. [9] In patients with hypertension [5, 10, 11] and chronic kidney disease (CKD) [12] high activation is associated with better blood pressure control and in patients with end-stage kidney disease higher activation is likely to improve uptake of home dialysis. [13]

Low activation levels have been reported in 25-40% of the general population [14] and in patients living with chronic diseases. [12, 15, 16] However, activation levels may vary considerably depending on the severity of the chronic disease. [17, 18] Indeed, little is known about the activation levels of patients with multiple and complex chronic diseases, including co-morbid diabetes and CKD. Among patients with diabetes and CKD, a sufficient degree of activation is required for patients to perform self-management behaviors such as blood glucose monitoring and medication self-management. [19] Moreover, as these patients face competing treatment demands especially when treatment recommendations for one condition conflict with or impede management of the other, or when patients prioritize one condition over another, [20-22] understanding the degree of patient activation becomes even more important.

Missed opportunities to enhance activation among patients with diabetes and CKD may result in more rapid progression of CKD and development of associated complications. [23] Additionally, activation levels may fluctuate as the disease progresses and complications arise necessitating matched changes in activation behaviour. [24]

Given the importance of patient activation for self-management in people with diabetes and CKD and ultimately patient outcomes, it is important to establish the level of activation in these patients and determine the patient and disease characteristics that influence activation. Consequently, the purpose of the present study was to 1) examine to what degree patients with co-morbid diabetes and CKD are activated and 2) identify what modifiable risk factors are independently associated with activation levels in patients with co-morbid diabetes and CKD.

METHODS

Study design and participants

A cross-sectional study was conducted (as previously described) [25] of patients attending diabetes and renal outpatient clinics of four public tertiary hospitals in Victoria and New South Wales (Monash Health, Alfred Health, Royal North Shore Hospital and Concord Hospital) from January to December 2014. Participants were eligible if they received their usual care at these hospitals and had a diagnosis of diabetes (either type 1 or type 2) and chronic kidney disease stages 3 to 5 (eGFR<60 mL/min). The diagnosis of diabetes followed the World Health Organisation definition [26] and was recorded from patients' prior inpatient or outpatient contacts. Patients were recruited prospectively from clinics and asked to complete a number of questionnaires which included the Diabetes Renal Project (Patient Survey), Diabetes Renal Project (Doctors Survey), the Patient Activation Measure (PAM-13), the Kidney Disease Quality of Life short form (KDQoL ^{TM}-36) and the Summary of Diabetes

Self-Care Activities (SDSCA) questionnaire (Supplementary Appendices 1, 2, 3, 4 and 5). The Diabetes Renal Project (Patient Survey) collected demographic information (age, gender, country of birth, language spoken at home) and clinical characteristics such as duration of diabetes and CKD. For each patient the site study staff or the clinician, using standardised procedures that included health assessment templates also completed a corresponding clinical survey, the Diabetes Renal Project (Doctors Survey) (Supplementary Appendix 2). The questionnaire collected information on patients' medical history, clinical findings, access to medical care for diabetes and CKD, medications and investigations such as blood test results. All participants were provided with written informed consent and 317 agreed to participate. This study was approved by all local hospital and university Human Research Ethics Committees (Monash Health Human Research Ethics Committee, Alfred Health Research Ethics Committee, Monash University Human Research Ethics Committee, Northern Sydney Local Health District Human Research Ethics Committee, Sydney Local Health District Human Research Ethics Committee and the University of Sydney Human Research Ethics Committee).

Demographic and clinical variables

Age, gender, socio-economic status (SES), stage of kidney disease, duration of kidney disease and duration of diabetes were all recorded as possible determinants of patient activation. Socio-economic status was estimated using the Australian Bureau of Statistics data. [27] Postcodes were coded according to the Index of Relative Social Disadvantage (IRSD), a composite measure based on selected census variables, which include income, educational attainment and employment status. The IRSD scores for each postcode were then grouped into quintiles for analysis, where the highest quintile comprised 20% of postcodes with the highest IRSD scores (the most advantaged areas).

CKD stage as defined by the Kidney Disease: Improving Global Outcomes (KDIGO) was used to define severity of the disease. [28] Duration of CKD was analysed as a continuous variable. Estimated GFR was calculated using the CKD EPI formula GFR = 141 X min (Scr/κ, 1) $^{\alpha}$ X max (Scr/κ, 1)$^{-1.209}$ X 0.993^{Age} X 1.018 X 1.159 where Scr is serum creatinine (mg/dL), κ is 0.7 for females and 0.9 for males, α is –0.329 for females and –0.411 for males, min indicates the minimum of Scr/κ or 1, and max indicates the maximum of Scr/κ or 1. [29] We used the CKD Epi formula because it is routinely reported in Australia [30] as the equation of choice and is recommended by the Kidney Disease, Improving Global Outcomes (KDIGO) guidelines[31].

Self-care

Self-care was assessed by the SDSCA questionnaire[32], which is a self-report measure of how often participants performed diabetes self-care activities. The SDSCA questionnaire has been utilised in several studies and settings and is considered to be reliable, valid, and sensitive[33-35] in evaluating self-care among adults with diabetes. This study used a version of the SDSCA questionnaire that included items assessing five domains of diabetes self-management which are; general diet (2 items), specific diet (2 items), exercise (2 items), blood glucose testing (2 items), and foot care (2 items) [32]. The medication self-management domain was excluded because of its ceiling effects and lack of variability among participants[32]. The smoking self-management domain was also excluded because smoking behaviour was relevant to smokers only.

Health Related quality of life

Health related quality of life was assessed using the English version of the Kidney Disease and Quality of Life (KDQoL^{TM}-36) questionnaire, which is a 36-item HRQoL survey with five subscales, namely the SF-12 measure of physical and mental functioning, burden of

kidney disease, symptom/problems list and the effects of kidney disease subscales. [36] Item scores were summed for each scale and transformed on a scale of 0 to 100 with a higher score indicating better HRQoL. [29] The validity and reliability of the Kidney Disease and Quality of Life (KDQoLTM-36) questionnaire has been reported previously. [37, 38, 39].

Patient activation

A 13-item survey-based scale called the short form of the Patient Activation Measure (PAM-13) that groups patients along a four-point levelling scale based on how activated patients are was used to measure patient activation. It has similar reliability and validity to the 22-item version across different ages, genders and health condition status. [40] The validity and reliability of the PAM-13 has also been tested in various regions and in patients with different conditions. [41-44] Each item of the form was scored on the 5-point Likert response scale. The raw scores were transformed from the original metric to a 0–100 metric with higher scores indicating higher activation levels. Based on the patient activation score, patients were categorized into four levels: level 1 (score <47.0), level 2 (score 47.1–55.1), level 3 (score 55.2–67.0), and level 4 (score >67.0) [40] . The activation levels were then dichotomized into low activation (Levels 1 and 2) and high activation (Levels 3 and 4) as reported in previous studies. [45, 46]

Data analysis

Normally distributed data are presented with mean and standard deviation (SD) as the measures of central tendency and dispersion, respectively. Correspondingly, non-normally distributed continuous data are presented with median and interquartile range (IQR, thus 25th and 75th percentiles), respectively. All HRQoL subscales were treated as continuous variables. First, the four patient activation levels were dichotomized into low activation group (Levels 1 and 2) and high activation group (Levels 3 and 4). Second, chi-squared or t-tests (as

appropriate) were used to analyse differences or associations between patient and disease characteristics and patient activation. Third, using the PAM score as a continuous variable, univariable regression models were performed in which each covariate was controlled for separately to ascertain its potential importance. Covariates that reached a significance level of $p<0.10$ or were of clinical importance were included in stepwise backward multivariable linear regression models that investigated the factors associated with patient activation for the entire study population and stratified analyses according to gender [47]. Potential covariates were age, gender, subscales of HRQoL, eGFR, body mass index, SES and the composite self-care score. Confidence intervals (CIs) were reported at the 95% level and for all analyses, a p value <0.05 was considered statistically significant. Cases with missing values were not included in the analyses after checking for the amount of missing data (the rate of missing data was minimal to result in any substantial loss of statistical power, <1% for some variables). There was no pattern in the missing data on any variables. All analyses were performed with IBM SPSS version 22 (Armonk, NY: IBM Corp.) or Stata version 12.1 (Statacorp, College Station, TX).

RESULTS

Patient characteristics

A total of 3028 patients were screened, 317 studied and of those 305 included in the analyses after the exclusion of 9 patients who had their eGFR misclassified (>60ml/min/m2) and 3 patients who had incomplete PAM data (Fig 1). There were no differences in age, gender and stage of kidney disease (for one study site) between patients who participated and those who did not participate in the study (Table S1). The baseline demographic and clinical characteristics of the study population are shown in Table 1. The median age and interquartile range (IQR) was 68 and 14.8 years respectively with 59% of the population being over 68

years old and 30% were women. The patients were evenly distributed across groups defined by SES and stage of kidney disease. Approximately 20% were receiving dialysis treatment.

Patient activation scores were normally distributed across the study population (mean 57.6, SD 15.5); men (mean 57.4, SD 16.0) and women patients (mean 58.1, SD 14.4) (Figure 2A and B). Twenty-two percent of patients were categorised as having level 1 PA, 23.6% level 2 PA, 36.4% level 3 PA and 18% level 4 PA (indicating greatest activation) (Figure 3). The proportions of the patients with low (levels 1 and 2) and high activation (levels 3 and 4) scores were 46% and 54% respectively (Figure 3).

Patients in the low activation group had significantly worse self-reported health in the burden of kidney disease and mental composite summary subscales than patients in the high activation group as shown in Table 1 (all $p<0.05$). No other differences between low and high activation groups were found for demographic factors (age, gender and socioeconomic status) and disease factors that included stage and duration of CKD, dialysis status, duration of diabetes and BMI (Table 1).

Factors associated with patient activation in the study population

On univariable analysis (Table 2), factors associated with lower activation were worse self-reported health in all HRQOL subscales, greater renal impairment (lower eGFR) and lower self-care scores. On multivariable analysis, older age, worse self-reported health in the burden of kidney disease subscale and lower self-care scores were independently associated with lower activation (Table 2).

Factors associated with patient activation stratified by gender

Tables S2 and S3 show stratified analyses according to gender. On univariable analysis, worse self-reported health in the symptom problems list, burden of kidney disease, mental

composite summary subscales and lower self-care scores were associated with lower activation in men. Worse self-reported health in all HRQOL subscales and lower eGFR were associated with lower activation in women. On multivariable analysis, worse self-reported health in the mental composite subscale was independently associated with lower activation in men, and worse self-reported health in the symptom problem list and greater renal impairment (lower eGFR) were independently associated with lower activation in women.

DISCUSSION

Amongst patients with co-morbid diabetes and CKD, we document for the first time in this study that patient activation is low, and identify factors independently associated with lower patient activation. We report significantly worse self-reported health in the burden of kidney disease and mental composite subscales for patients in the low activation group compared to those in the high activation group. Lower activation was also independently associated with older age, having worse self-reported health in the burden of kidney disease subscale and lower self-care scores across the entire study population. In men, worse self-reported health in the mental composite subscale was associated with lower activation. In women worse self-reported health in the symptom problem list (with symptoms including sore muscles, chest pain, cramps, itchy or dry skin and shortness of breath, faintness/dizziness, and lack of appetite) and greater renal impairment were associated with lower patient activation.

The mean patient activation level was 57.6 on a theoretical scale of 0–100 and was comparable to the means cited in several studies across other regions and disease conditions.[15, 41, 48] Patient activation in patients with co-morbid diabetes and CKD was generally low with close to 50% of our study population reporting low levels of activation. This is greater than that of the general population where 25 to 40% have reported low activation [14] and in patients with diabetes where 20 to 30% reported low activation. [47, 49]

Conversely in patients with CKD alone (eGFR<60 mL/min/1.73m^2), patient activation has been observed to be even lower with over 65% of one study cohort [17] reporting low activation levels. Although we expected that diabetes and CKD in combination would lead to lower activation compared to either diabetes or CKD alone, our results suggest an improvement in patient activation among patients with diabetes and CKD. This may be attributed to a focus on self-management of diabetes. More studies are required to confirm this observation.

We found that older age was independently associated with lower activation. Similar findings have been reported in people with diabetes [8, 16, 27] other chronic diseases [44, 46, 50-52] and in a national survey of US adults. [53] The reason for this could be a higher prevalence of depressive symptoms and functional difficulties impairing self-management in older patients.[50, 51] In contrast, other studies in different populations found conflicting evidence, showing no direct relationship between patient activation and age. [2, 54-56] These inconsistencies may be due to differences in clinical and demographic characteristics of the populations studied. For example, it has been previously reported that younger patients with CKD have poor coping strategies compared to older patients [57] and this may potentially lead to low activation. Our results highlight a subgroup at risk of lower activation, which may benefit from targeted interventions to improve activation. These interventions may include encouraging younger patients to ask questions[58] when they attend medical appointments and training their peers to lead such interventions[59]. Additionally, the contradictions regarding the relationship between age and patient activation highlight that intervention strategies cannot exclusively be based on the knowledge of patients' demographics, but should include other modifiable factors as well.

In line with previous studies of patients with conditions other than co-morbid diabetes and CKD, [15, 50, 53, 60-62] patient activation was low in those with worse self-reported health status.

Our study showed that lower mental health composite scores on KDQoL were independently associated with lower patient activation, particularly in men. This could be due to men with co-morbid disease having less ability to cope with multiple conditions than women, [63] resulting in lower levels of activation. Men with chronic disease may also have less coping ability because they do not seek help as often as women do.[64] Given the high prevalence of mental disorders such as depression in patients with CKD, [65] addressing mental health issues may be very important for enhancing patient activation and outcomes.

Our data suggest that greater renal impairment in women may be associated with lower activation. The most likely explanation for this is that women tend to have lower physical functioning [66, 67] which is associated with lower patient activation[62] even in the early stages of CKD.[17, 53] Another plausible explanation is that women may receive less support from their care givers compared to men due to caregiver stress and fatigue [68] associated with managing chronic diseases. The lack of support in managing chronic diseases may lead to lower activation among women. Additionally, due to the complexity of diabetes and CKD, there is limited time to address all patient needs resulting in lower quality medical care for discordant conditions.[69]

Interestingly, we did not find a significant association between SES and patient activation. This is in contrast to other studies that have reported patient activation to vary by SES with individuals from lower SES groups reported as less activated than those from higher SES groups. [6, 14] These discordant findings could be attributable to our use of postcode as a surrogate for SES, which may not accurately represent SES.

Strengths and limitations

Our findings should be interpreted in light of the strengths and limitations of our study design. The strengths include the inclusion of several biologic and non-biological patient variables

such as gender, age, SES, HRQoL, BMI and disease duration as potential factors influencing patient activation since the determinants are likely to be multifactorial. The study was conducted across multiple sites increasing the generalizability of the findings [70] and we also used validated and disease-specific instruments for measuring HRQoL (KDQoL™-36) and patient activation (PAM 13™). The limitations include that our findings may not be generalised to culturally and linguistically diverse (CALD) populations. The cross sectional design of the study did not permit assessment of temporal effects or the potential for reverse causality with low activation causing poor health. Longitudinal studies are needed to better understand the effects over time of factors influencing patient activation in this population.

Conclusions

In conclusion, in patients with co-morbid diabetes and CKD patient activation was low, with almost half of patients reporting low activation. Older age and worse self-reported health were associated with lower activation. This data may serve as the basis for the development of interventions needed to enhance activation and outcomes for patients with diabetes and CKD.

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Contributors

EZ, CL and SZ conceptualised the study. EZ, CL, SR and SZ performed data curation. EZ designed the analysis in consultation with CL, SR, GF, SJ, PK, KP, GR, RW, and SZ. EZ drafted the original draft and all authors reviewed and edited the final manuscript.

Conflicts of Interest

The authors declare no conflicts of interest in relation to this work.

Ethics approval

Approval for the Diabetes Renal Project (DRP) was obtained from Monash University, Monash Health, Alfred Health, Royal North Shore Hospital and Concord Hospital.

Data sharing statement

Data for the DRP study can be shared for specific research questions that are available from the corresponding author on request.

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Table 1: Patient characteristics by activation status (N=305)

	Patient activation status		*p*-value [1]
	Low level N (%)	High level N (%)	
Age			
<68 years	68 (49.3)	88 (53.3)	0.48
≥68 years	70 (50.7)	77 (46.7)	
Gender			
Women	42 (30.4)	51 (30.9)	0.93
Men	96 (69.6)	114 (69.1)	
Socio-economic status [2], n: (%)			0.86
Upper	24 (17.4)	34 (20.6)	
Upper middle	32 (23.2)	31 (18.8)	
Lower middle	27 (19.6)	34 (20.6)	
Upper lower	28 (20.3)	31 (18.8)	
Lower	27 (19.6)	35 (21.2)	
CKD [3] duration in years: mean (SD)	8.8 (9.6)	9.2 (11.6)	0.74
Stage of CKD [4]			0.86
3a	30 (21.7)	42 (25.5)	
3b	35 (25.4)	42 (25.5)	
4	34 (24.6)	40 (24.2)	
5	39 (28.3)	41 (24.8)	
Diabetes duration in years: mean (SD)	17.1 (12.0)	18.2 (11.8)	0.40
Body mass index: mean, n: (%)			
Underweight	1 (1.4)	1 (1.2)	0.60
Health weight	17 (24.3)	15 (17.4)	
Overweight	21 (30.0)	23 (26.7)	
Obese	47 (67.1)	31 (36.0)	
Dialysis status			
Current	29 (21.0)	30 (18.2)	0.54
Predialysis	109 (79.0)	135 (81.8)	
HRQOL[5]: mean (SD)			
Symptom/problem list	72.0 (17.6)	75.5 (17.4)	0.08
Effect of kidney disease	71.0 (23.5)	74.1 (23.6)	0.27
Burden of kidney disease	55.9 (29.5)	63.3 (31.9)	0.04
Physical composite summary	34.4 (11.3)	36.0 (11.0)	0.26
Mental composite summary	45.5 (10.5)	48.3 (11.0)	0.03

Data are presented in N (%) unless otherwise indicated. [1] T-test for mean differences and chi-square test for differences in proportions; [2] Socio-economic status was estimated using the Australian Bureau of Statistics data. Postcodes were coded according to the Index of Relative Social Disadvantage, a composite measure based on selected census variables, which include income, educational attainment and employment status, [3] chronic kidney disease, [4] Stage of CKD-Stage 5 CKD included patients on dialysis (n=59) and not on dialysis (n=21) [5] Health related quality of life

Table 2: Univariable and multivariable regression model for factors associated with low activation in the study population

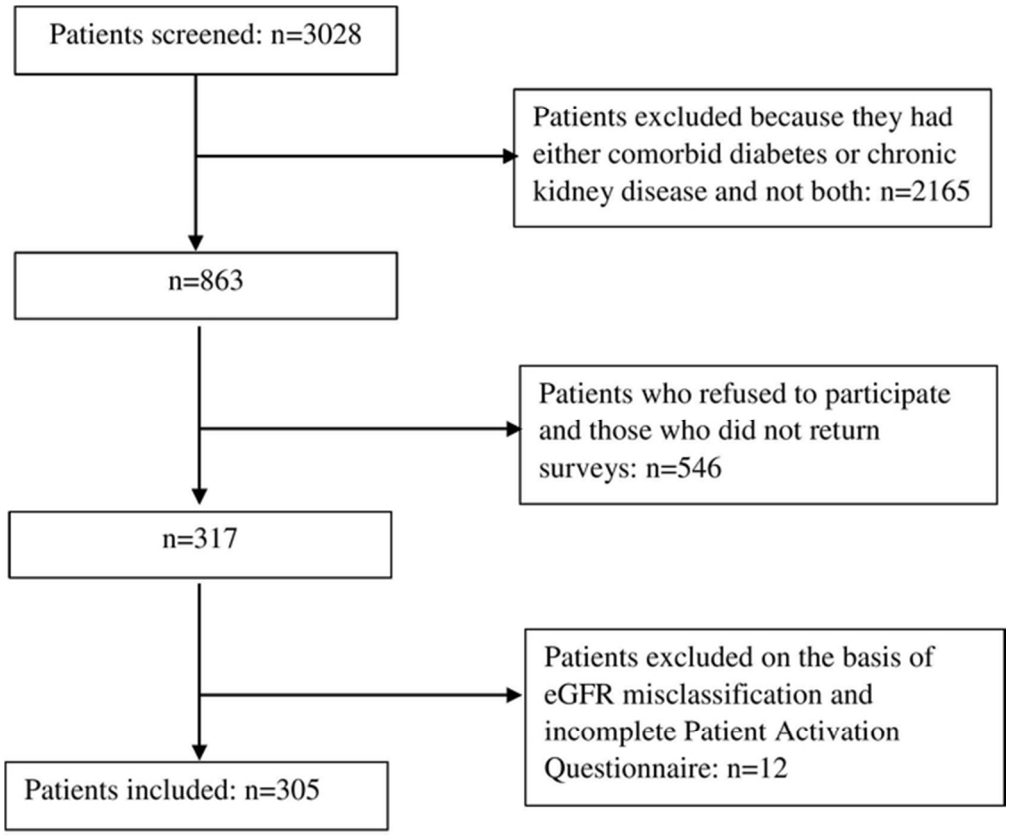
Variables	Univariable B (95% CI)	Multivariable B (95% CI)
Age	-0.05 (-0.22 to 0.11)	-0.18 (-0.35 to -0.01)*
Gender		
Men	Ref	Ref
Women	-0.79 (-4.59 to 3.02)	-
Health related quality of life		
Symptom problem list	0.15 (0.05 to 0.25)**	-
Effects of kidney disease	0.09 (0.02 to 0.17)*	-
Burden of kidney disease	0.11 (0.05 to 0.16)***	0.11 (0.05 to 0.17)***
Physical composite summary	0.17 (0.01 to 0.33)*	-
Mental composite summary	0.26 (0.09 to 0.42)**	-
Duration of diabetes	-0.02 (-0.17 to 0.13)	-
Duration of kidney disease	0.07 (-0.11 to 0.25)	-
eGFR [1]	0.11 (0.00 to 0.21)*	0.01 (-0.12 to 0.15)
Body mass index		
Healthy weight [2]	Ref	Ref
Overweight	-2.78 (-7.75 to 2.20)	-
Obese	1.98)-2.03 to 5.99)	-
Socioeconomic status [3]		
Lower	Ref	Ref
Lower middle	-0.31 (-4.75 to 4.12)	-
Upper lower	-1.42 (-5.80 to 2.95)	-
Upper middle	-0.95 (-5.27 to 3.38))	-
Upper	3.17 (-1.28 7.62)	-
Self-care composite score	0.21 (0.06 to 0.37)**	0.18 (0.02 to 0.35)*

*p<0.05; **p<0.01, ***p<0.001; 1-per 1ml/min increase in eGFR; 2-due to small numbers of underweight patients (N=2), the underweight group was combined with the health weight group for this analysis; 3-Socio-economic status was estimated using the Australian Bureau of Statistics data. Postcodes were coded according to the Index of Relative Social Disadvantage (IRSD), a composite measure based on selected census variables, which include income, educational attainment and employment status.

Figure 1: Patient inclusion flow diagram

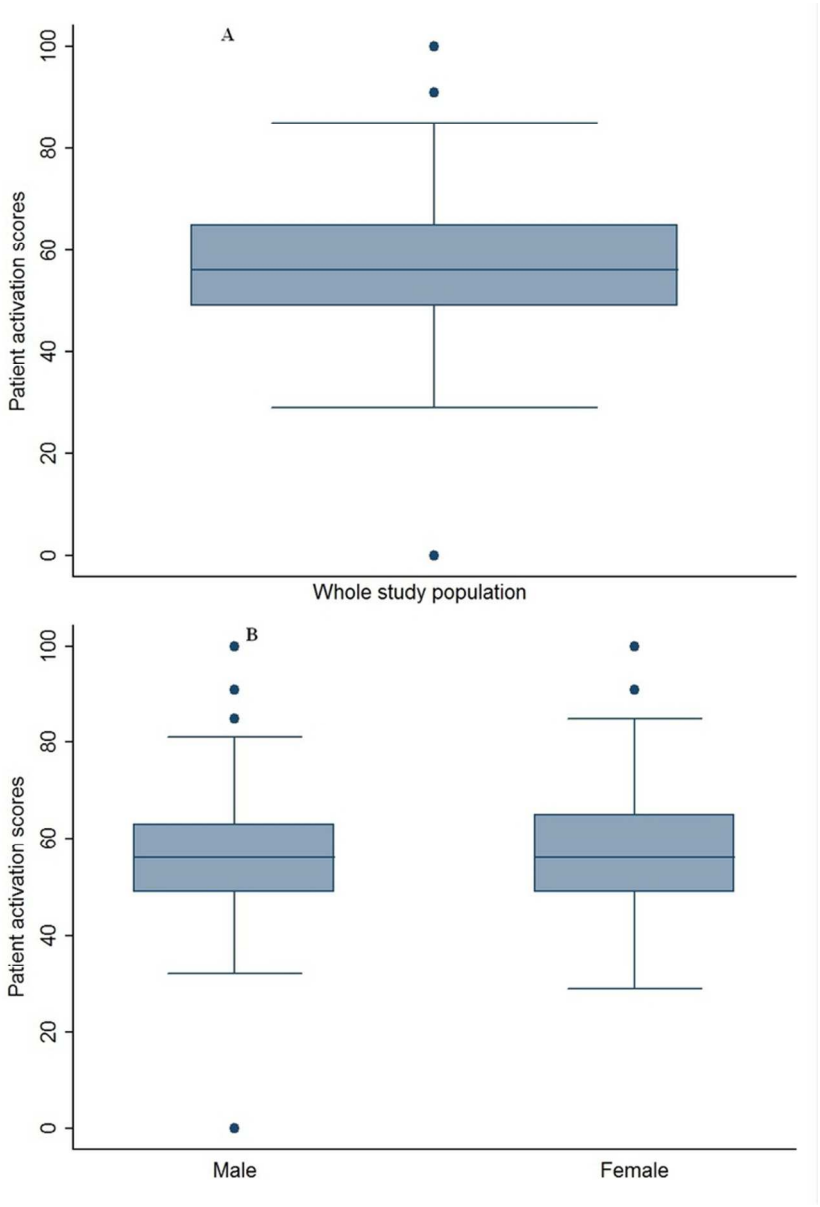
Figure 2: Patient activation. Distribution of patient activation from (A) the study population (mean 57.6, SD 15.5) and (B) men (mean 57.4, SD 16.0) and women patients (mean 58.1, SD 14.4)

Figure 3: Distribution of participants across the four levels of patient activation. Level 1 (score of 0.0–47.0) indicates that a person may not yet understand that their role as a patient is important. Level 2 (47.1– 55.1) indicates that a person lacks the confidence and knowledge to take action. Level 3 (55.2– 67) indicates that a person is beginning to take action and level 4 (67.1–100) indicates that a person is proactive about health and engages in many recommended health behaviors



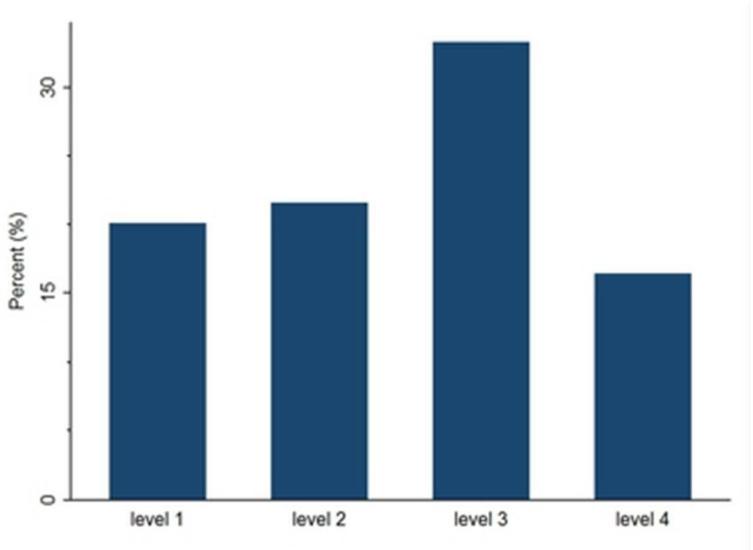
Patient inclusion flow diagram

58x48mm (300 x 300 DPI)



Patient activation. Patient activation. Distribution of patient activation from (A) the study population (mean 57.6, SD 15.5) and (B) men (mean 57.4, SD 16.0) and women patients (mean 58.1, SD 14

63x92mm (300 x 300 DPI)



Distribution of participants across the four levels of patient activation. Level 1 (score of 0.0–47.0) indicates that a person may not yet understand that their role as a patient is important. Level 2 (47.1– 55.1) indicates that a person lacks the confidence and knowledge to take action. Level 3 (55.2– 67) indicates that a person is beginning to take action and level 4 (67.1–100) indicates that a person is proactive about health and engages in many recommended health behaviors

31x23mm (300 x 300 DPI)

S1: Characteristics of patients who did and did not participate in the study at one hospital site

	Responders	**Non-responders**	**p-value**
Patient numbers (n)	127	243	
Age (SD)	66.6 (10.8)	68.9 (11.9)	0.06
Gender (Female)	30.7	39.5	0.10
CKD stage (KDOQI %)			
3	34.2	40.9	
4	25.2	25.5	
5	33.9	40.3	0.37

KDOQI-Kidney Disease Outcomes Quality Initiative classification of stages of chronic kidney disease

S2: Univariable and multivariable regression model for factors associated with low activation in men with diabetes and chronic kidney disease

Variables	Univariable B (95% CI)	Multivariable B (95% CI)
Age	-0.11 (-0.32 to 0.12)	-
Health related quality of life		
Symptom problem list	0.12 (0.04 to 0.25)*	-
Effects of kidney disease	0.04 (-0.05 to 0.13)	-
Burden of kidney disease	0.08 (0.01 to 0.15)*	-
Physical composite summary	0.06 (-0.15 to 0.26)	-
Mental composite summary	0.23 (0.03 to 0.43)*	0.23 (0.02 to 0.44)*
Duration of diabetes	0.01 (-0.17 to 0.20)	-
Duration of kidney disease	0.10 (-0.12 to 0.16)	-
eGFR	0.03 (-0.12 to 0.16)	-
Body mass index		
Healthy weight [1]	Ref	Ref
Overweight	-5.08 (-10.96 to 0.80)	-
Obese	2.87 (-2.08 to 7.81)	-
Socioeconomic status [2]		
Lower	Ref	Ref
Lower middle	0.41 (-5.04 to 5.85)	-
Upper lower	-0.63 (-5.98 to 4.73)	-
Upper middle	-2.23 (-7.37 to 2.92)	-
Upper	4.65 (-1.04 to 10.33)*	-
Self-care composite score	0.21 (0.01 to 0.40)*	-

*p<0.05; **p<0.01, ***p<0.001; 1-due to small numbers of underweight patients (N=2), the underweight group was combined with the healthy weight group for this analysis; 2-Socio-economic status was estimated using the Australian Bureau of Statistics data. Postcodes were coded according to the Index of Relative Social Disadvantage, a composite measure based on selected census variables, which include income, educational attainment and employment status.

S3: Univariable and multivariable regression model for factors associated with low activation in women with diabetes and chronic kidney disease

Variables	Univariable B (95% CI)	Multivariable B (95% CI)
Age	0.02 (-0.21 to 0.26)	-
Health related quality of life		
Symptom problem list	0.21 (0.06 to 0.36)**	0.2 (0.05 to 0.35)**
Effects of kidney disease	0.21 (0.09 to 0.33)**	-
Burden of kidney disease	0.18 (0.09 to 0.27)***	-
Physical composite summary	0.45 (0.19 to 0.71)**	-
Mental composite summary	0.33 (0.05 to 0.60)*	-
Duration of diabetes	-0.09 (-0.35 to 0.17)	-
Duration of kidney disease	0.02 (-0.31 to 0.27)	-
eGFR	0.27 (0.10 to 0.43)**	0.27 (0.11 to 0.44)**
Body mass index		
Healthy weight [1]	Ref	Ref
Overweight	4.85 (-4.75 to 14.40)	-
Obese	-0.66 (-7.00 to 6.87)	-
Socioeconomic status [2]		
Lower	Ref	Ref
Lower middle	-1.99 (-9.71 to 5.73)	-
Upper lower	-3.33 (-11.03 to 4.38)	-
Upper middle	-3.40 (-4.93 to 11.73)	-
Upper	0.27 (-6.88 to 7.42)	-
Self-care composite score	0.23 (-0.06 to 0.53	-

p<0.05; **p<0.01, ***p<0.001; 1-due to small numbers of underweight patients (N=2), the underweight group was combined with the healthy weight group for this analysis; 2-Socio-economic status was estimated using the Australian Bureau of Statistics data. Postcodes were coded according to the Index of Relative Social Disadvantage, a composite measure based on selected census variables, which include income, educational attainment and employment status.

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Hospital ID: Site Staff ID: Participant ID:

DRP: Diabetes Renal Project - (Patient Survey - Health Experiences)

Thank-you for participating in this large multi-centre research project, called the Diabetes Renal Project (DRP). This National Health and Medical Research Council (NHMRC) partnership project is being conducted by Monash University, in partnership with Monash Health, Alfred Health, Royal North Shore Hospital, Concord Repatriation General Hospital, The George Institute for Global Health, Diabetes Australia, and Kidney Health Australia.

INSTRUCTIONS

PLEASE:
Use a black **BIRO**, (DO NOT use a pencil or a fountain or felt tip pen)

Please **PRINT** in **CAPITAL** letters and stay within the box provided for text.

If you make a **mistake when writing**, cross it out with one thick line and write your correct answer above the box.

To answer a multiple choice question place a **CROSS INSIDE** the box like this: X

If you make a **mistake**, place a diagonal line through the incorrect answer like this: X and then put a cross in the box of your preferred response.

Write dates using leading zeros (e.g. **6th April 2011 = 06/04/2011**)

DO NOT USE liquid paper to correct mistakes.

AVOID folding the form.

Please complete every page of the questionnaire. Sometimes questions may seem very similar or repetitious but they are all a little different, so please answer each question.

THANK YOU

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Hospital ID: Site Staff ID: Participant ID:

Date day / month / year

Part 1: Health Indicators (Patient Survey)

Section 1: General Information

1. Age (years)

2. Country of birth _____

3. Main language spoken at home?

☐ English ☐ Italian ☐ Spanish ☐ Greek

☐ Arabic ☐ Vietnamese ☐ Cantonese ☐ Hindi

☐ Mandarin ☐ Other, (please specify) → _____

Section 2: Diabetes

4. What type of diabetes do you have? ☐ Type 1 ☐ Type 2 ☐ Unsure ☐ Other

5. How many years have you had diabetes? *years* *months*

6. How do you manage your diabetes? *(select all that apply)*

☐ Diet and lifestyle only ☐ Insulin injections (3 or fewer per day)

☐ Tablets to lower blood glucose ☐ Insulin injections (4 or more per day)

☐ Byetta injections (2 per day) ☐ Insulin pump therapy

☐ Other (please specify) → _____

7. If you use insulin how confident are you in self- adjusting your insulin dose? *(select one option)*

Not at all confident ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 *Extremely Confident*

Section 3: Kidney Disease

8. How many years have you had kidney disease? *years* *months*

9. Did you develop kidney disease as a result of your diabetes? ☐ No ☐ Yes ☐ Unsure

Section 4: Medication

10. Who explains your medications to you? *(select all that apply)*

☐ GP ☐ Diabetes nurse

☐ GP Practice Nurse ☐ Kidney doctor at a public hospital clinic

☐ Private kidney specialist ☐ Diabetes doctor at a public hospital clinic

☐ Kidney nurse ☐ Pharmacist

☐ Private endocrinologist/diabetes specialist

☐ Other (please specify) → _____

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Hospital ID: Site Staff ID: Participant ID:

Section 4: Medication (cont)

11. Which health professional(s) do you see to manage your diabetes and kidney disease? *(select all that apply)*

- ☐ GP
- ☐ GP Practice Nurse
- ☐ Private kidney specialist
- ☐ Kidney nurse
- ☐ Private endocrinologist/diabetes specialist
- ☐ Diabetes nurse
- ☐ Kidney doctor at a public hospital clinic
- ☐ Diabetes doctor at a public hospital clinic
- ☐ Dietitian
- ☐ Podiatrist
- ☐ Optometrist
- ☐ Ophthalmologist
- ☐ Other (please specify) → _____

12. Please record the last time you saw the following health professionals. (S*elect the appropriate frequency for each professional)*

		0-3 months ago	4-6 months ago	7-12 months ago	Over 12 months ago	Never	Uncertain
a.	Endocrinologist (diabetes doctor)	☐	☐	☐	☐	☐	☐
b.	Nephrologist (kidney doctor)	☐	☐	☐	☐	☐	☐
c.	Diabetes Nurse Educator	☐	☐	☐	☐	☐	☐
d.	Kidney Nurse Practitioner	☐	☐	☐	☐	☐	☐
e.	Optometrist	☐	☐	☐	☐	☐	☐
f.	Ophthalmologist	☐	☐	☐	☐	☐	☐
g.	Podiatrist	☐	☐	☐	☐	☐	☐
h.	Dentist	☐	☐	☐	☐	☐	☐
i.	Dietitian	☐	☐	☐	☐	☐	☐
j.	Social Worker	☐	☐	☐	☐	☐	☐

13. If you run out of medication what would you do? (S*elect all that apply)*

- ☐ Obtain a supply from my local pharmacy, even if I didn't have a prescription
- ☐ Obtain a prescription from my GP then have it filled at my local pharmacy
- ☐ Wait until I next saw a doctor to obtain another prescription
- ☐ I never run out because I always ensure I have a spare supply

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Section 5. Barriers and support

14. Barriers causing difficulty in caring for your diabetes and kidney disease *(Mark disagree or somewhat disagree or somewhat agree or agree to each listed barrier. Please choose only one option per barrier).*

	Disagree	Somewhat disagree	Somewhat agree	Agree
a. My diabetes and kidney specialist does not spend enough time with me	☐	☐	☐	☐
b. My diabetes and kidney specialist does not provide me with enough information/education about my diabetes and kidney disease	☐	☐	☐	☐
c. I am often seen by a different doctor each time I attend my diabetes or kidney disease appointment	☐	☐	☐	☐
d. My specialists give me conflicting advice	☐	☐	☐	☐
e. I do not have a good relationship with my specialist or other specialist health service staff	☐	☐	☐	☐
f. Specialist health service staff are not caring, polite and helpful	☐	☐	☐	☐
g. My specialists do not communicate well with my GP	☐	☐	☐	☐
h. My specialists don't communicate well with each other	☐	☐	☐	☐
i. I do not have a good GP	☐	☐	☐	☐
j. I need more education and understanding of my diabetes	☐	☐	☐	☐
k. I need more education and understanding of my kidney disease	☐	☐	☐	☐
l. The information provided by my doctors or health professionals is hard to understand because English is not my first language or the information is not culturally relevant	☐	☐	☐	☐
m. The information provided by my doctors or health professionals is too complicated	☐	☐	☐	☐
n. It is difficult to obtain medical support and advice for my diabetes when I need it	☐	☐	☐	☐
o. It is difficult to obtain medical support and advice for my kidney disease when I need it	☐	☐	☐	☐
p. I have had an unsatisfactory prior experience with a diabetes or kidney health service/specialist	☐	☐	☐	☐
q. I am unable to afford the cost of attending appointments or buying medication for my diabetes	☐	☐	☐	☐
r. I have trouble adjusting to the impact that diabetes and kidney disease has made on my life and/or that of my family and friends	☐	☐	☐	☐
s. My diabetes and kidney disease makes me feel very unwell	☐	☐	☐	☐
t. My other illnesses affect my ability to look after my diabetes and kidney disease	☐	☐	☐	☐

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Section 5: Barriers and support (cont)

	Disagree	Somewhat disagree	Somewhat agree	Agree
u. I have many other stressors in my life, and taking care of my diabetes and kidney disease is not a high priority	☐	☐	☐	☐
v. My job makes it difficult to take care of my diabetes and kidney disease well	☐	☐	☐	☐
w. My mood (e.g. feeling down, worried, frustrated) gets in the way of me looking after my diabetes and kidney disease	☐	☐	☐	☐
x. I do not feel motivated enough to look after my diabetes and kidney disease well	☐	☐	☐	☐
y. I have trouble maintaining the right diet or fluid restriction for my diabetes and kidney disease	☐	☐	☐	☐
z. I have difficulty knowing what I can eat/drink, for my diabetes and kidney disease	☐	☐	☐	☐
aa. I experience unpleasant side-effects from my medication	☐	☐	☐	☐
bb. I do not receive support from my family	☐	☐	☐	☐
cc. I do not receive support from my friends	☐	☐	☐	☐
dd. I find it difficult to get services for home-help	☐	☐	☐	☐

ee. Please list any additional problems: _____

_____

Section 6: Diabetes Service and Kidney Service

15. Are you registered with the National Diabetes Service Scheme (NDSS)? *This service supports people living with diabetes by providing subsidised blood glucose strips and free insulin pen needles/syringes. It is not the same as being a member of Diabetes Australia.* ☐ No ☐ Yes

16. Do you have difficulty in accessing a diabetes service?

☐ No → Skip to Q 17

☐ Yes → **16.1. Why is it difficult for you to access a diabetes service?** *(select all that apply)*

- ☐ No private transport e.g. car/ driver
- ☐ Parking (e.g. cost, locality to the clinic)
- ☐ Disability
- ☐ Cost (e.g. appointments, prescription costs)
- ☐ Time of appointment (e.g. during work hours)
- ☐ Location of the service (e.g. distance from home)
- ☐ Time spent each week at dialysis
- ☐ I have too many appointments
- ☐ Long waiting times before I get an appointment
- ☐ Long waiting times in the waiting room before I see a doctor
- ☐ I don't have a problem with accessing a service
- ☐ Other (please specify) → _____

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Section 6: Diabetes Service and Kidney Service (cont)

17. How satisfied are you with the care provided by your diabetes service? *(select one option)*

Not at all satisfied ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 *Extremely Satisfied*

18. Do you have difficulty in accessing a kidney service?

☐ No → Skip to Q 19

☐ Yes → **18.1. Why is it difficult for you to access a kidney service?** *(select all that apply)*

- ☐ No private transport e.g. car/ driver
- ☐ Parking (e.g. cost, locality to the clinic)
- ☐ Disability
- ☐ Cost (e.g. appointments, prescription costs)
- ☐ Time of appointment (e.g. during work hours)
- ☐ Location of the service (e.g. distance from home)
- ☐ Other (please specify) →
- ☐ Time spent each week at dialysis
- ☐ I have too many appointments
- ☐ Long waiting times before I get an appointment
- ☐ Long waiting times in the waiting room before I see a doctor
- ☐ I don't have a problem with accessing a service

19. How satisfied are you with the care provided by your kidney service? *(select one option)*

Not at all satisfied ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 *Extremely Satisfied*

20. An ideal health service to look after my diabetes and kidney disease would include: *(please cross either no or yes in the table below)*

a. Regular contact with a case manager, nurse or doctor who knows my entire medical history and who will help me coordinate the management of my health	☐ No	☐ Yes
b. Education sessions to help me manage my diabetes, including information about correct food choices and what support is available	☐ No	☐ Yes
c. Education sessions to help me manage my kidney disease, including information about correct food choices and what support is available	☐ No	☐ Yes
d. Education sessions for my family so that they can understand my condition	☐ No	☐ Yes
e. Education sessions targeted to the public/community about diabetes and kidney disease	☐ No	☐ Yes
f. Education handouts that are culturally relevant, in my native language, easy to understand, and in an appropriate format (e.g. DVD)	☐ No	☐ Yes
g. Seeing the same doctor or health professional when I attend my diabetes and kidney disease appointments	☐ No	☐ Yes
h. All my doctors giving me the same information/advice, instead of conflicting information/advice	☐ No	☐ Yes
i. Good communication between my doctors	☐ No	☐ Yes
j. Centralised Electronic health medical records with investigation results, which all my doctors can access	☐ No	☐ Yes
k. Friendly, caring, supportive and knowledgeable staff and medical professionals	☐ No	☐ Yes

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Section 6: Diabetes Service and Kidney Service (cont)

l. A combined multidisciplinary clinic with both diabetes and kidney doctors, as well as other health staff (such as dietitian, nurse educators, podiatrists etc) in the one place	☐ No	☐ Yes
m. Shorter waiting times in the waiting room	☐ No	☐ Yes
n. Routine access to a psychologist for emotional support	☐ No	☐ Yes
o. Routine access to a dietitian	☐ No	☐ Yes
p. Routine access to a podiatrist	☐ No	☐ Yes
q. Routine access to an eye doctor	☐ No	☐ Yes
r. Routine access to a diabetes nurse educator	☐ No	☐ Yes
s. Routine access to a kidney nurse	☐ No	☐ Yes
t. Routine access to a pharmacist	☐ No	☐ Yes
u. Routine access to a social worker	☐ No	☐ Yes
v. Routine access to an occupational therapist	☐ No	☐ Yes
w.Routine review by doctors and health professionals for my diabetes and kidney disease (e.g. diabetes doctor, dietitian, podiatrist) while I am on dialysis	☐ No	☐ Yes
x. Appointment reminders (e.g. phone call/text message/email) prior to my appointment	☐ No	☐ Yes
y. Incentives to staff members to provide good patient service (e.g. Monthly prize)	☐ No	☐ Yes
z. Debriefing groups and education sessions for staff members to improve patient care	☐ No	☐ Yes
aa. Affordable parking close to clinic/dialysis	☐ No	☐ Yes
bb. Diabetes and renal services being offered in my local community, rather than primarily based in the hospital	☐ No	☐ Yes
cc. 24 hour hotline to staff in case I need advice or assistance	☐ No	☐ Yes

Section 7: Summary of Diabetes Self Care Activities for Diabetes and Kidney Disease

Please recall the last 7 days that you were well when answering the following questions. (Please select one response per question).

Diet

21. How many of the last 7 days have you followed a healthy eating plan?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

22. Over the past month how many days per week have you followed your eating plan?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

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Hospital ID: ☐ Site Staff ID: ☐☐☐☐☐ Participant ID: ☐☐☐☐

Section 7: Summary of Diabetes Self Care Activities for Diabetes and Kidney Disease (cont)

23. On how many of the last 7 days did you eat five or more servings of fruit?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

24. On how many of the last 7 days did you eat high fat foods such as red meat or full dairy products?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

Excercise

25. On how many of the last 7 days did you participate in at least 30min of exercise?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

26. On how many of the last 7 days did you participate in a specific exercise session?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

Blood Sugar Testing

27. On how many of the last 7 days did you test your blood sugar?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

28. On how many of the last 7 days did you test your blood sugar the number of times recommended by your health care provider?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

Foot Care

29. On how many of the last 7 days did you check your feet?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

30. On how many of the last 7 days did you inspect the inside of your shoes?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

Smoking

31. Have you smoked or taken a puff of a cigarette in the last 7 days?

☐ No → Skip to Q 32

☐ Yes → **31.1 How many cigarettes did you smoke on an average day?** ☐☐☐

Medications

32. On how many of the last 7 days did you take your recommended diabetes medication?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

33. On how many of the last 7 days did you take your recommended insulin injections?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

34. On how many of the last 7 days did you take your recommended number of diabetes pills?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

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DRP: Diabetes Renal Project (Doctors Survey - Health Indicators)

Thank-you for participating in this large multi-centre research project, called the Diabetes Renal Project (DRP). This National Health and Medical Research Council (NHMRC) partnership project is being conducted by Monash University, in partnership with Monash Health, Alfred Health, Royal North Shore Hospital, Concord Repatriation General Hospital, The George Institute for Global Health, Diabetes Australia, and Kidney Health Australia.

INSTRUCTIONS

PLEASE:
Use a black **BIRO**, (DO NOT use a pencil or a fountain or felt tip pen)

Please **PRINT** in **CAPITAL** letters and stay within the box provided for text.

If you make a **mistake when writing**, cross it out with one thick line and write your correct answer above the box.

To answer a multiple choice question place a **CROSS INSIDE** the box like this: X

If you make a **mistake**, place a diagonal line through the incorrect answer like this: X and then put a cross in the box of your preferred response.

Write dates using leading zeros (e.g. **6th April 2011 = 06/04/2011**)

DO NOT USE liquid paper to correct mistakes.

AVOID folding the form.

Please complete every page of the questionnaire. Sometimes questions may seem very similar or repetitious but they are all a little different, so please answer each question.

THANK YOU

27311

Hospital ID: Site Staff ID: Participant ID:

Date day / month / year

Health Indicators (Doctors Survey)

Section 1: Demographic of Patient Participant

1. Age *(years)*

2. Gender ☐ Male ☐ Female

3. Participant Post-code

4. Aboriginal background ☐ No ☐ Yes

5.Torres Strait Islander background ☐ No ☐ Yes

6. Maori/Pacific Strait Islander background ☐ No ☐ Yes

7. Is the participant a current smoker ?

☐ No → Skip to Q 8

☐ Yes → **7.1. Average number of cigarettes smoked per day?**

8. Has the participant previously smoked ?

☐ No → Skip to Q 9

☐ Yes → **8.1. Average number of cigarettes smoked per day?**

9. Does the participant currently drink alcohol?

☐ No → Skip to Q 10

☐ Yes → **9.1. Average number of standard drinks per week?**

Section 2: Examination Findings

Please complete with the most recent examination findings and date of examination

10. Blood Pressure - *(the average of 3 readings measured after 5 minutes sitting)*

/ mmHg → **10.1** day / month / year

11. Heart Rate Bpm → **11.1** day / month / year

12. Weight . Kg → **12.1** day / month / year

13. Height . Metres → **13.1** day / month / year

At the most recent examination, does the participant have the following conditions:

14a. New loss of vibratory sensation (both feet)

☐ No ☐ Yes → Date of examination **14a.1** day / month / year

☐ Not examined/unknown

14b. New loss of ankle reflexes (both legs)

☐ No ☐ Yes → Date of examination **14b.1** day / month / year

☐ Not examined/unknown

14c. New loss of light touch (eg. loss of pressure sensation with 10gm force monofilament)

☐ No ☐ Yes → Date of examination **14c.1** day / month / year

☐ Not examined/unknown

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Hospital ID: Site Staff ID: Participant ID:

Section 2: Examination Findings (cont)

15. Foot ulcers

☐ No ☐ Yes → Date of examination **15.1** day / month / year

☐ Not examined/unknown

16. Foot deformity

☐ No ☐ Yes → Date of examination **16.1** day / month / year

☐ Not examined/unknown

Section 3: Medical History

17. Diabetes Type ☐ Type 1 ☐ Type 2 **18. Duration of diabetes** *years* *months*

OR ☐ Unknown/not documented

Has the participant experienced any of the following complications/comorbidities?

19. Ischemic Heart Disease?	☐ No	☐ Yes	**23. Peripheral Neuropathy?**	☐ No	☐ Yes
20. Stroke?	☐ No	☐ Yes	**24. Diabetic Nephropathy?**	☐ No	☐ Yes
21. Peripheral Vascular disease?	☐ No	☐ Yes	**25. Hypertension**	☐ No	☐ Yes
22. Diabetic Retinopathy?	☐ No	☐ Yes	**26. Dyslipidemia**	☐ No	☐ Yes

27. Does the participant have a family history of heart disease? ☐ No ☐ Yes

OR ☐ Unknown/not documented

---

28. Duration of nephrological care *years* *months* **OR** ☐ Unknown/not documented

29. Kidney disease stage *(select one option)* ☐ Stage 3a ☐ Stage 3b ☐ Stage 4 ☐ Stage 5

30. Is the patient currently on dialysis?

☐ No → Skip to Q 31

☐ Yes → **30.1 Haemodialysis** ☐ No ☐ Yes → **30.2** Number of months on dialysis

30.3 Peritoneal ☐ No ☐ Yes → **30.4** Number of months on dialysis

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Hospital ID: Site Staff ID: Participant ID:

Section 3: Medical History (cont)

31. Prior to their current dialysis, has the patient been on any other form of dialysis?

☐ No → Skip to Q 32

☐ Yes→ **31.1 Haemodialysis?** ☐ No ☐ Yes

Date commenced **31.2** ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year)

Date ceased **31.3** ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year)

31.4 Peritoneal dialysis? ☐ No ☐ Yes

Date commenced **31.5** ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year)

Date ceased **31.6** ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year)

32. Has the patient had a kidney transplant?

☐ No → Skip to Q 33

☐ Yes→ **32.1 Date of transplant** ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year)

OR ☐ Unknown/not documented

Section 4: Medical Care of Diabetes and Chronic Kidney Disease

33. How often does the participant monitor his/her diabetes with a blood glucose monitor? *(select one option)*

☐ ≥ 3 times per day ☐ Once per day (daily) ☐ Once per week (weekly) ☐ Uncertain

☐ 2 times per day ☐ A few times per week ☐ Rarely ☐ Not documented

34. Please indicate when the participant was last referred/seen by the following health professionals. *(Select the appropriate response for each health professional).*

	Not referred/reviewed by this health professional	3 months or less	4-12 months ago	13-24 months ago	As required	Uncertain
a. Endocrinologist	☐	☐	☐	☐	☐	☐
b. Nephrologist	☐	☐	☐	☐	☐	☐
c. Diabetes Nurse Educator	☐	☐	☐	☐	☐	☐
d. Renal Nurse Practitioner	☐	☐	☐	☐	☐	☐
e. Optometrist	☐	☐	☐	☐	☐	☐
f. Ophthalmologist	☐	☐	☐	☐	☐	☐
g. Podiatrist	☐	☐	☐	☐	☐	☐
h. Dentist	☐	☐	☐	☐	☐	☐
i. Dietician	☐	☐	☐	☐	☐	☐
j. Social Worker	☐	☐	☐	☐	☐	☐

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Hospital ID: Site Staff ID: Participant ID:

Section 5: Medications

35. Is the participant on Insulin?

☐ No → Skip to Q 36

☐ Yes→ **35.1 Is the participant on an Insulin pump?** ☐ No ☐ Yes

35.2 What type of insulin? *(select all that apply)*

☐ Long acting ☐ Short acting ☐ Rapid acting ☐ Basal

36. Is the participant on diabetes tablets?

☐ No → Skip to Q 34

☐ Yes→ **Does the participant take:**

36.1 Metformin?	☐ No	☐ Yes
36.2 Sulphonylurea?	☐ No	☐ Yes
36.3 Glitazone?	☐ No	☐ Yes
36.4 Acarbose?	☐ No	☐ Yes
36.5 Gliptin (DPP4 inhibitor)?	☐ No	☐ Yes
36.6 GLP1 agonist? (e.g exenatide or liraglutide)	☐ No	☐ Yes
36.7 SGLT2 inhibitors?	☐ No	☐ Yes

36.8 Other diabetes medication *(please list below)*

37. Other medications - is the participant taking:

37.1 ACE inhibitor?	☐ No	☐ Yes
37.2 Angiotensin2 Receptor Blocker?	☐ No	☐ Yes
37.3 Other Antihypertensives?	☐ No	☐ Yes
37.4 Statin?	☐ No	☐ Yes
37.5Fibrate?	☐ No	☐ Yes
37.6 Erythropoieting Stimulating Agent?	☐ No	☐ Yes
37.7 Phosphate binder?	☐ No	☐ Yes
37.8 Iron Supplementation (IV or Oral)?	☐ No	☐ Yes

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Hospital ID: ☐ Site Staff ID: ☐☐☐☐☐ Participant ID: ☐☐☐☐

Section 6: Investigations

38. Has a HbA1c test been performed in the last 3 months? ☐ No ☐ Yes

Please record the most recent HbA1c result

38.1 HbA1c ☐☐☐ mmol/mol ***and*** **38.2** ☐☐.☐ % → **38.3** Date of test ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year)

39. Please enter details below of the most recent lipid profile results:

39.1 Total Cholesterol ☐☐.☐ mmol/L

39.2 LDL Cholesterol ☐.☐☐ mmol/L

39.3 HDL Cholesterol ☐☐.☐☐ mmol/L

39.4 Triglycerides ☐.☐☐ mmol/L

39.5 Date of test ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year)

OR ☐ Not tested

40. Please enter details below of the most recent serum biochemistry profile results:

40.1 Potassium ☐.☐ mmol/L

40.2 Creatinine ☐☐☐☐ µmol/L

40.3 Calcium ☐.☐☐ mmol/L

40.4 Phosphate ☐.☐☐ mmol/L

40.5 Parathyroid hormone (PTH) ☐☐☐.☐
(result within last 6 months)

40.5.1 Units ☐ pmol/L ☐ ng/L

OR ☐ Not done within the past 6 months

40.6 eGFR ☐☐☐ mL/min per 1.73m^2

40.7 Albumin ☐☐☐ g/L

40.8 Date of test ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year)

(For PTH, please record result from within the past 6 months of this date)

OR ☐ Not tested

41. Please record the most recent spot urine albumin / creatinine ratio (ACR):

☐☐☐☐.☐☐ mg/mmol **40.1 Date of test** ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year) **OR** ☐ Not tested

42. If you have used another method to measure microalbumin / proteinuria please record details below:

☐☐☐☐.☐☐ **42.1 Units** ☐ mg/L ☐ mg/24hr ☐ µg/min ☐ g/mmol ☐ g/L

42.2 Date of test ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year) **OR** ☐ Not tested

43. Please enter the most recent Haemoglobin test result: ☐☐☐ g/L **43.1 Date of test** ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year)

OR ☐ Not tested

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Hospital ID: Site Staff ID: Participant ID:

Date ___ / ___ / ____ (day / month / year)

Patient Activation Measure (PAM) 13™ ©Insignia Health, LLC 2013

Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by crossing your answer. Your answers should be what is true for you and not just what you think others want you to say. If the statement does not apply to you, cross N/A. (Please choose only one response for each statement).

	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
1. When all is said and done, I am the person who is responsible for taking care of my health	☐	☐	☐	☐	☐
2. Taking an active role in my own health care is the most important thing that affects my health	☐	☐	☐	☐	☐
3. I am confident that I can help prevent or reduce problems associated with my health	☐	☐	☐	☐	☐
4. I know what each of my prescribed medications do	☐	☐	☐	☐	☐
5. I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself	☐	☐	☐	☐	☐
6. I am confident that I can tell a doctor concerns I have even when he or she does not ask	☐	☐	☐	☐	☐
7. I am confident that I can follow through on medical treatments I may need to do at home	☐	☐	☐	☐	☐
8. I understand my health problems and what causes them	☐	☐	☐	☐	☐
9. I know what treatments are available for my health problems	☐	☐	☐	☐	☐
10. I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising	☐	☐	☐	☐	☐
11. I know how to prevent problems with my health	☐	☐	☐	☐	☐
12. I am confident I can figure out solutions when new problems arise with my health	☐	☐	☐	☐	☐
13. I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress	☐	☐	☐	☐	☐

Your Health

– *and* –

Well-Being

Kidney Disease and Quality of Life (KDQOL™-36)

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Thank you for completing these questions!

Study of Quality of Life For Patients on Dialysis

What is the purpose of the study?

This study is being carried out in cooperation with physicians and their patients. The purpose is to assess the quality of life of patients with kidney disease.

What will I be asked to do?

For this study, we want you to complete a survey today about your health, how you feel and your background.

Confidentiality of information?

We do not ask for your name. Your answers will be combined with those of other participants in reporting the findings of the study. Any information that would permit identification of you will be regarded as strictly confidential. In addition, all information collected will be used only for purposes of the study, and will not be disclosed or released for any other purpose without your prior consent.

How will participation benefit me?

The information you provide will tell us how you feel about your care and further understanding about the effects of medical care on the health of patients. This information will help to evaluate the care delivered.

Do I have to take part?

You do not have to fill out the survey and you can refuse to answer any question. Your decision to participate will not affect your opportunity to receive care.

Your Health

This survey includes a wide variety of questions about your health and your life. We are interested in how you feel about each of these issues.

1. In general, would you say your health is: [Mark an ☒ in the one box that best describes your answer.]

Excellent	Very good	Good	Fair	Poor
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? [Mark an ☒ in a box on each line.]

	Yes, limited a lot	Yes, limited a little	No, not limited at all
2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	☐ 1	☐ 2	☐ 3
3. Climbing several flights of stairs	☐ 1	☐ 2	☐ 3

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	Yes	No
4. Accomplished less than you would like.....	☐ 1	☐ 2
5. Were limited in the kind of work or other activities	☐ 1	☐ 2

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	Yes	No
6. Accomplished less than you would like.....	☐ 1	☐ 2
7. Didn't do work or other activities as carefully as usual	☐ 1	☐ 2

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks…

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
9. Have you felt calm and peaceful?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
10. Did you have a lot of energy?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
11. Have you felt downhearted and blue?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

12. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Your Kidney Disease

How true or false is each of the following statements for you?

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
13. My kidney disease interferes too much with my life	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
14. Too much of my time is spent dealing with my kidney disease	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
15. I feel frustrated dealing with my kidney disease	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
16. I feel like a burden on my family	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

During the <u>past 4 weeks</u>, to what extent were you bothered by each of the following?

	Not at all bothered	Somewhat bothered	Moderately bothered	Very much bothered	Extremely bothered
	▼	▼	▼	▼	▼
17. Soreness in your muscles?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
18. Chest pain?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
19. Cramps?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
20. Itchy skin?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
21. Dry skin?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
22. Shortness of breath?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
23. Faintness or dizziness?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
24. Lack of appetite?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
25. Washed out or drained?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
26. Numbness in hands or feet?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
27. Nausea or upset stomach?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
28[a]. (Hemodialysis patient only) Problems with your access site?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
28[b]. (Peritoneal dialysis patient only) Problems with your catheter site?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Effects of Kidney Disease on Your Daily Life

Some people are bothered by the effects of kidney disease on their daily life, while others are not. How much does kidney disease <u>bother</u> you in each of the following areas?

	Not at all bothered	Somewhat bothered	Moderately bothered	Very much bothered	Extremely bothered
29. Fluid restriction?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
30. Dietary restriction?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
31. Your ability to work around the house?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
32. Your ability to travel?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
33. Being dependent on doctors and other medical staff?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
34. Stress or worries caused by kidney disease?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
35. Your sex life?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
36. Your personal appearance?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Thank you for completing these questions!

The Summary of Diabetes Self- Care Activities for Diabetes and Kidney Disease

*The questions below ask you about your diabetes and kidney disease self-care activities during the past **7 days**. If you were sick during the past 7 days, please think back to the last 7 days that you were not sick.*

Diet

How many of the last SEVEN DAYS have you followed a healthful eating plan?

0 1 2 3 4 5 6 7

On average, **over the past month**, how many DAYS PER WEEK have you followed your eating plan?

0 1 2 3 4 5 6 7

On how many of the last SEVEN DAYS did you eat five or more servings of fruits and vegetables?

0 1 2 3 4 5 6 7

On how many of the last SEVEN DAYS did you eat high fat foods such as red meat or full-fat dairy products?

0 1 2 3 4 5 6 7

Exercise

On how many of the last SEVEN DAYS did you participate in at least 30 minutes of physical activity? (Total minutes of continuous activity, including walking).

0 1 2 3 4 5 6 7

On how many of the last SEVEN DAYS did you participate in a specific exercise session (such as swimming, walking, biking) other than what you do around the house or as part of your work?

0 1 2 3 4 5 6 7

Blood Sugar Testing

On how many of the last SEVEN DAYS did you test your blood sugar?

0 1 2 3 4 5 6 7

On how many of the last SEVEN DAYS did you test your blood sugar the number of times recommended by your health care provider?

0 1 2 3 4 5 6 7

Foot Care

On how many of the last SEVEN DAYS did you check your feet?

0 1 2 3 4 5 6 7

On how many of the last SEVEN DAYS did you inspect the inside of your shoes?

0 1 2 3 4 5 6 7

Smoking

Have you smoked a cigarette—even one puff—during the past SEVEN DAYS?

0. No

1. Yes.

If yes, how many cigarettes did you smoke on an average day?

Number of cigarettes: ……

Medications

On how many of the last SEVEN DAYS, did you take your recommended diabetes medication?

0 1 2 3 4 5 6 7

On how many of the last SEVEN days did you take your recommended insulin injections?

0 1 2 3 4 5 6 7

On how many of the last SEVEN days did you take your recommended number of diabetes pills?

0 1 2 3 4 5 6 7

Toobert et al. The Summary of Diabetes Self-Care Activities Measure. Diabetes Care, 23(7) July 2000: 943-950.

STROBE Statement—Checklist of items that should be included in reports of ***cross-sectional studies***

	Item No	Recommendation
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract (Page 2 and page 5)
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found (Page 2-abstract)
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported (Page 4 to 5 of the background)
Objectives	3	State specific objectives, including any prespecified hypotheses (Stated on page 5, second paragraph)
Methods		
Study design	4	Present key elements of study design early in the paper (Page 5, under methods)
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection (Page 5, under methods)
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants (Page 5, lines 18-24)
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable (Page 6 to 7)
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group (Page 6 and 7; health related quality of life and patient activation)
Bias	9	Describe any efforts to address potential sources of bias (Page 6 and 7, validated measures were used)
Study size	10	Explain how the study size was arrived at
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why (Page 7 under data analysis)
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding (Page 7 to 8)
		(*b*) Describe any methods used to examine subgroups and interactions (Page 8, lines 1 to 4)
		(*c*) Explain how missing data were addressed (Page 8, line 13-15)
		(*d*) If applicable, describe analytical methods taking account of sampling strategy (N/A)
		(*e*) Describe any sensitivity analyses
Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (Page 8, line 13)
		(b) Give reasons for non-participation at each stage
		(c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (Page 8, line 15 to 22)
		(b) Indicate number of participants with missing data for each variable of interest (Page 8, line 15 to 16)

Outcome data	15*	Report numbers of outcome events or summary measures
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (Page 9)
		(*b*) Report category boundaries when continuous variables were categorized
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period N/A
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses (Page 9, lines 14 to 22- subgroup analyses by gender)
Discussion		
Key results	18	Summarise key results with reference to study objectives (Page 10, lines 1 to 10)
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias (Page 12, lines page 12 to 16)
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence (page 10 to 11)
Generalisability	21	Discuss the generalisability (external validity) of the study results (Page 12, lines 9 to 12)
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based (Page 19, under funding)

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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Factors associated with patient activation in an Australian population with comorbid diabetes and chronic kidney disease: a cross sectional study

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Factors associated with patient activation in an Australian population with comorbid diabetes and chronic kidney disease: a cross sectional study

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Abstract

Objective To evaluate the extent of patient activation and factors associated with activation in adults with co-morbid diabetes and chronic kidney disease (CKD).

Design A cross sectional study.

Setting Renal/diabetes clinics of four tertiary hospitals across the two largest states of Australia.

Study population Adult patients (over 18 years) with co-morbid diabetes and CKD (eGFR <60 mL/min/1.73m^2).

Main outcome measures Patients completed the Patient Activation Measure, the Kidney Disease Quality of Life and demographic and clinical data survey from January to December 2014. Factors associated with patient activation were examined using chi-squared or t-tests and linear regression.

Results Three hundred and five patients with median age of 68 (interquartile range 14.8) years were studied. They were evenly distributed across socioeconomic groups, stage of kidney disease and duration of diabetes but not gender. Approximately 46% reported low activation. In patients with low activation, the symptom/problem list, burden of kidney disease and mental composite subscales scores were all significantly lower (all p<0.05). On multivariable analysis, factors associated with lower activation for all patients were older age, worse self-reported health in the burden of kidney disease subscale and lower self-care scores. Additionally, in men, worse self-reported health in the mental composite subscale was associated with lower activation and in women, worse self-reported health scores in the symptom problem list and greater renal impairment were associated with lower activation.

Conclusion Findings from this study suggest that levels of activation are low in patients with diabetes and CKD. Older age and worse self-reported health were associated with lower activation. This data may serve as the basis for the development of interventions needed to enhance activation and outcomes for patients with diabetes and CKD.

Key words

Patient activation; diabetes; chronic kidney disease; self-care; health related quality of life

Strengths and limitations of this study

- Several biologic and non-biological patient variables were included as potential factors influencing patient activation since the factors are likely to be multifactorial.
- The study was conducted across multiple sites increasing the generalizability of the findings.
- The limitations include that our findings may not be generalised to culturally and linguistically diverse (CALD) populations.
- The cross sectional design of the study did not permit us to assess temporal effects or to rule out the potential for reverse causality with low activation causing poor health.

INTRODUCTION

Patient activation may be defined as the ability and willingness of patients to take on the role of managing their own health and health care [1] and is related to the degree that a patient participates or engages in specific health behaviours. [2-4] Previous studies of hypertensive patients in primary care settings suggest that patient activation is associated with patient outcomes, where low activated patients are more likely to smoke, [5] have a higher body mass index (BMI) and less likely to achieve cholesterol and glycated haemoglobin (HbA1c) targets. [6] In patients with diabetes, high activation has been associated with greater engagement in exercise, [7] fewer hospitalisations [8] and improved glycemic control. [9] In patients with hypertension [5, 10, 11] and chronic kidney disease (CKD) [12] high activation is associated with better blood pressure control and in patients with end-stage kidney disease higher activation is likely to improve uptake of home dialysis. [13]

Low activation levels have been reported in 25-40% of the general population [14] and in patients living with chronic diseases. [12, 15, 16] However, activation levels may vary considerably depending on the severity of the chronic disease. [17, 18] Indeed, little is known about the activation levels of patients with multiple and complex chronic diseases, including co-morbid diabetes and CKD. Among patients with diabetes and CKD, a sufficient degree of activation is required for patients to perform self-management behaviors such as blood glucose monitoring and medication self-management. [19] Moreover, as these patients face competing treatment demands especially when treatment recommendations for one condition conflict with or impede management of the other, or when patients prioritize one condition over another, [20-22] understanding the degree of patient activation becomes even more important.

Missed opportunities to enhance activation among patients with diabetes and CKD may result in more rapid progression of CKD and development of associated complications. [23] Additionally, activation levels may fluctuate as the disease progresses and complications arise necessitating matched changes in activation behaviour. [24]

Given the importance of patient activation for self-management in people with diabetes and CKD and ultimately patient outcomes, it is important to establish the level of activation in these patients and determine the patient and disease characteristics that influence activation. Consequently, the purpose of the present study was to 1) examine to what degree patients with co-morbid diabetes and CKD are activated and 2) identify what modifiable risk factors are independently associated with activation levels in patients with co-morbid diabetes and CKD.

METHODS

Study design and participants

A cross-sectional study was conducted (as previously described) [25] of patients attending diabetes and renal outpatient clinics of four public tertiary hospitals in Victoria and New South Wales (Monash Health, Alfred Health, Royal North Shore Hospital and Concord Hospital) from January to December 2014. Participants were eligible if they received their usual care at these hospitals and had a diagnosis of diabetes (either type 1 or type 2) and chronic kidney disease stages 3 to 5 (eGFR<60 mL/min). The diagnosis of diabetes followed the World Health Organisation definition [26] and was recorded from patients' prior inpatient or outpatient contacts. Patients were recruited prospectively from clinics and the following questionnaires were completed; the Diabetes Renal Project (Patient Survey), Diabetes Renal Project (Doctors Survey), the Summary of Diabetes Self-Care Activities (SDSCA) questionnaire, the Kidney Disease Quality of Life short form (KDQoL ^{TM} -36) and the Patient

Activation Measure (PAM-13) (supplementary appendices 1, 2, 3, 4 and 5). The Diabetes Renal Project (Patient Survey) (see online supplementary appendix 1) collected demographic information (age, gender, country of birth, language spoken at home) and clinical characteristics such as duration of diabetes and CKD. For each patient the site study staff or the clinician, using standardised procedures that included health assessment templates also completed a corresponding clinical survey, the Diabetes Renal Project (Doctors Survey) (see online supplementary appendix 2). The questionnaire collected information on patients' medical history, clinical findings, access to medical care for diabetes and CKD, medications and investigations such as blood test results. All participants were provided with written informed consent and 317 agreed to participate. All local hospital and university Human Research Ethics Committees (Monash Health Human Research Ethics Committee, Alfred Health Research Ethics Committee, Monash University Human Research Ethics Committee, Northern Sydney Local Health District Human Research Ethics Committee, Sydney Local Health District Human Research Ethics Committee and the University of Sydney Human Research Ethics Committee) approved this study.

Demographic and clinical variables

Age, gender, socio-economic status (SES), stage of kidney disease, duration of kidney disease and duration of diabetes were all recorded as possible determinants of patient activation. SES was estimated using the Australian Bureau of Statistics data.[27] Postcodes were coded according to the Index of Relative Social Disadvantage (IRSD), a composite measure based on selected census variables, which include income, educational attainment and employment status. The IRSD scores for each postcode were then grouped into quintiles for analysis, where the highest quintile comprised 20% of postcodes with the highest IRSD scores (the most advantaged areas).

CKD stage as defined by the Kidney Disease: Improving Global Outcomes (KDIGO) was used to define severity of the disease. [28] Duration of CKD was analysed as a continuous variable. Estimated GFR was calculated using the CKD EPI formula GFR = 141 X min $(Scr/\kappa, 1)^{\alpha}$ X max $(Scr/\kappa, 1)^{-1.209}$ X 0.993^{Age} X 1.018 X 1.159 where Scr is serum creatinine (mg/dL), κ is 0.7 for females and 0.9 for males, α is –0.329 for females and –0.411 for males, min indicates the minimum of Scr/κ or 1, and max indicates the maximum of Scr/κ or 1. [29] We used the CKD Epi formula because it is routinely reported in Australia [30] as the equation of choice and is recommended by the Kidney Disease, Improving Global Outcomes (KDIGO) guidelines[31].

Self-care

Self-care was assessed by the SDSCA questionnaire[32], which is a self-report measure of how often participants performed diabetes self-care activities (see online supplementary appendix 3). The SDSCA measures several dimensions of diabetes self-management with adequate internal and test-retest reliability, and evidence of validity and sensitivity to change[32]. An overall Cronbach's α coefficient of 0.63 has been reported[33]. The SDSCA questionnaire has been utilised in several studies and settings [34-36] to evaluate self-care among adults with diabetes. This study used a version of the SDSCA questionnaire that included items assessing five domains of diabetes self-management which are; general diet (2 items), specific diet (2 items), exercise (2 items), blood glucose testing (2 items), and foot care (2 items) [32]. The medication self-management domain was excluded because of its ceiling effects and lack of variability among participants[32]. The smoking self-management domain was also excluded because smoking behaviour was relevant to smokers only.

Health Related quality of life

Health related quality of life was assessed using the English version of the Kidney Disease and Quality of Life (KDQoL^{TM}-36) questionnaire (see online supplementary appendix 4), which is a 36-item HRQoL survey with five subscales, namely the SF-12 measure of physical and mental functioning, burden of kidney disease, symptom/problems list and the effects of kidney disease subscales. [37] Item scores were summed for each scale and transformed on a scale of 0 to 100 with a higher score indicating better HRQoL. [29] The validity and reliability of the Kidney Disease and Quality of Life (KDQoLTM-36) questionnaire has been reported previously. [38, 39, 40]

Patient activation

A 13-item survey-based scale called the short form of the Patient Activation Measure (PAM-13) that groups patients along a four-point levelling scale based on how activated patients are was used to measure patient activation (see online supplementary appendix 5). It has similar reliability and validity to the 22-item version across different ages, genders and health condition status (Cronbach's alpha of 0.91 and a Rasch person statistic of 0.81 for the real and 0.85 for the model on which it was based).[3, 41] The validity and reliability of the PAM-13 has also been tested in various regions and in patients with different conditions. [42-45] Each item of the form was scored on the 5-point Likert response scale. The raw scores were transformed from the original metric to a 0–100 metric with higher scores indicating higher activation levels. Based on the patient activation score, patients were categorized into four levels: level 1 (score <47.0), level 2 (score 47.1–55.1), level 3 (score 55.2–67.0), and level 4 (score >67.0) [41] . The activation levels were then dichotomized into low activation (Levels 1 and 2) and high activation (Levels 3 and 4) as reported in previous studies. [46, 47]

Data analysis

Normally distributed data are presented with mean and standard deviation (SD) as the measures of central tendency and dispersion, respectively. Correspondingly, non-normally distributed continuous data are presented with median and interquartile range (IQR, thus 25th and 75th percentiles), respectively. All HRQoL subscales were treated as continuous variables. First, the four patient activation levels were dichotomized into low activation group (Levels 1 and 2) and high activation group (Levels 3 and 4). Second, chi-squared or t-tests (as appropriate) were used to analyse differences or associations between patient and disease characteristics and patient activation. Third, using the PAM score as a continuous variable, univariable regression models were performed in which each covariate was controlled for separately to ascertain its potential importance. Covariates that reached a significance level of $p<0.10$ or were of clinical importance were included in stepwise backward multivariable linear regression models that investigated the factors associated with patient activation for the entire study population and stratified analyses according to gender [48]. Potential covariates were age, gender, subscales of HRQoL, eGFR, body mass index, SES and the composite self-care score. Confidence intervals (CIs) were reported at the 95% level and for all analyses, a p value <0.05 was considered statistically significant. Cases with missing values were not included in the analyses after checking for the amount of missing data which was minimal (less than 1%) for variables such as age, eGFR, SES and duration of diabetes and kidney disease. There was no pattern in the missing data on any variables. All analyses were performed with IBM SPSS version 22 (Armonk, NY: IBM Corp.) or Stata version 12.1 (Statacorp, College Station, TX).

RESULTS

Patient characteristics

A total of 3028 patients were screened, 317 studied and of those 305 included in the analyses after the exclusion of nine patients who had their eGFR misclassified (>60ml/min/m^2) and three patients who had incomplete PAM data (Fig 1). There were no differences in age, gender and stage of kidney disease (for one study site) between patients who participated and those who did not participate in the study (see online supplementary table S1). The baseline demographic and clinical characteristics of the study population are shown in table 1. The median age and interquartile range (IQR) was 68 and 14.8 years respectively with 59% of the population being over 68 years old and 30% were women. The patients were evenly distributed across groups defined by SES and stage of kidney disease. Approximately 20% were receiving dialysis treatment.

Patient activation scores were normally distributed across the study population (mean 57.6, SD 15.5); men (mean 57.4, SD 16.0) and women patients (mean 58.1, SD 14.4) (figure 2A and B). Twenty-two percent self-reported PAM level 1, 23.6% level 2, 36.4% level 3 and 18% level 4 (indicating greatest activation) (figure 3). The proportions of the patients with low (levels 1 and 2) and high activation (levels 3 and 4) scores were 46% and 54% respectively (figure 3).

Patients in the low activation group had significantly worse self-reported health in the burden of kidney disease and mental composite summary subscales than patients in the high activation group as shown in table 1 (all $p<0.05$). No other differences between low and high activation groups were found for demographic factors (age, gender and socioeconomic status) and disease factors that included stage and duration of CKD, dialysis status, duration of diabetes and BMI (table 1).

Factors associated with patient activation in the study population

On univariable analysis (table 2), factors associated with lower activation were worse self-reported health in all HRQoL subscales, greater renal impairment (lower eGFR) and lower self-care scores. On multivariable analysis, older age, worse self-reported health in the burden of kidney disease subscale and lower self-care scores were independently associated with lower activation (table 2).

Factors associated with patient activation stratified by gender

Online supplementary tables S2 and S3 show stratified analyses according to gender. On univariable analysis, worse self-reported health in the symptom problems list, burden of kidney disease, mental composite summary subscales and lower self-care scores were associated with lower activation in men. Worse self-reported health in all HRQoL subscales and lower eGFR were associated with lower activation in women. On multivariable analysis, worse self-reported health in the mental composite subscale was independently associated with lower activation in men, and worse self-reported health in the symptom problem list and greater renal impairment (lower eGFR) were independently associated with lower activation in women.

DISCUSSION

Amongst patients with co-morbid diabetes and CKD, we document for the first time in this study that patient activation is low, and identify factors independently associated with lower patient activation. We report significantly worse self-reported health in the burden of kidney disease and mental composite subscales for patients in the low activation group compared to those in the high activation group. Lower activation was also independently associated with older age, having worse self-reported health in the burden of kidney disease subscale and lower self-care scores across the entire study population. In men, worse self-reported health

in the mental composite subscale was associated with lower activation. In women worse self-reported health in the symptom problem list (with symptoms including sore muscles, chest pain, cramps, itchy or dry skin and shortness of breath, faintness/dizziness, and lack of appetite) and greater renal impairment were associated with lower patient activation.

The mean patient activation score was 57.6 on a theoretical scale of 0–100 and was comparable to the means cited in several studies across other regions and disease conditions.[15, 42, 49] Patient activation in patients with co-morbid diabetes and CKD was generally low with close to 50% of our study population reporting low levels of activation. This is greater than that of the general population where 25 to 40% have reported low activation [14] and in patients with diabetes where 20 to 30% reported low activation. [48, 50] Conversely in patients with CKD alone (eGFR<60 mL/min/1.73m^2), patient activation has been observed to be even lower with over 65% of one study cohort [17] reporting low activation levels. Although we expected that diabetes and CKD in combination would lead to lower activation compared to either diabetes or CKD alone, our results suggest higher patient activation among patients with diabetes and CKD. This may be attributed to a focus on self-management of diabetes. More studies are required to confirm this observation.

We found that older age was independently associated with lower activation. Similar findings have been reported in people with diabetes [8, 16, 27] other chronic diseases [45, 47, 51-53] and in a national survey of US adults. [54] The reason for this could be a higher prevalence of depressive symptoms and functional difficulties impairing self-management in older patients.[51, 52] In contrast, other studies in different populations found conflicting evidence, showing no direct relationship between patient activation and age. [2, 55-57] These inconsistencies may be due to differences in clinical and demographic characteristics of the populations studied. For example, it has been previously reported that younger patients with

CKD have poorer coping strategies compared to older patients [58], which may lead to low activation or could possibly be due to low activation. Our results highlight a subgroup at risk of lower activation, which may benefit from targeted interventions to improve activation. These interventions may include encouraging patients to ask questions[59] when they attend medical appointments and training their peers to lead such interventions[60]. Additionally, the contradictions regarding the relationship between age and patient activation highlight that intervention strategies cannot exclusively be based on the knowledge of patients' demographics, but should include other modifiable factors as well.

In line with previous studies of patients with conditions other than co-morbid diabetes and CKD, [15, 51, 54, 61-63] patient activation was low in those with worse self-reported health status. Our study showed that lower mental health composite scores on KDQoL were independently associated with lower patient activation, particularly in men. This could be due to men with co-morbid disease having less ability to cope with multiple conditions than women, [64] resulting in lower levels of activation. Men with chronic disease may also have less coping ability because they do not seek help as often as women do.[65] Given the high prevalence of mental disorders such as depression in patients with CKD, [66] addressing mental health issues may be very important for enhancing patient activation and outcomes.

Our data suggest that greater renal impairment in women may be associated with lower activation. The most likely explanation for this is that women tend to have lower physical functioning [67, 68] which is associated with lower patient activation[63] even in the early stages of CKD.[17, 54] Another plausible explanation is that women may receive less support from their care givers compared to men due to caregiver stress and fatigue [69] associated with managing chronic diseases. The lack of support in managing chronic diseases may lead to lower activation among women. Additionally, due to the complexity of diabetes and CKD, there is

limited time to address all patient needs resulting in lower quality medical care for discordant conditions.[70]

Interestingly, we did not find a significant association between SES and patient activation. This is in contrast to other studies that have reported patient activation to vary by SES with individuals from lower SES groups reported as less activated than those from higher SES groups. [6, 14] These discordant findings could be attributable to our use of postcode as a surrogate for SES, which may not accurately represent SES.

Strengths and limitations

Our findings should be interpreted in light of the strengths and limitations of our study design. The strengths include the inclusion of several biologic and non-biological patient variables such as gender, age, SES, HRQoL, BMI and disease duration as potential factors influencing patient activation since the determinants are likely to be multifactorial. The study was conducted across multiple sites increasing the generalizability of the findings [71] and we also used validated and disease-specific instruments for measuring HRQoL (KDQoL™-36) and patient activation (PAM 13™). The limitations include that our findings may not be generalised to culturally and linguistically diverse (CALD) populations. The cross sectional design of the study did not permit assessment of temporal effects or the potential for reverse causality with low activation causing poor health. Longitudinal studies are needed to better understand the effects over time of factors influencing patient activation in this population.

Conclusions

In conclusion, in patients with co-morbid diabetes and CKD patient activation was low, with almost half of patients reporting low activation. Older age and worse self-reported health were associated with lower activation. This data may serve as the basis for the development

of interventions needed to enhance activation and outcomes for patients with diabetes and CKD.

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Contributors

EZ, CL and SZ conceptualised the study. EZ, CL, SR and SZ performed data curation. EZ designed the analysis in consultation with CL, SR, GF, SJ, PK, KP, GR, RW, and SZ. EZ drafted the original draft and all authors reviewed and edited the final manuscript.

Conflicts of Interest

The authors declare no conflicts of interest in relation to this work.

Ethics approval

Approval for the Diabetes Renal Project (DRP) was obtained from Monash University, Monash Health, Alfred Health, Royal North Shore Hospital and Concord Hospital.

Data sharing statement

Data for the DRP study can be shared for specific research questions that are available from the corresponding author on request.

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Table 1: Patient characteristics by activation status (N=305)

	Patient activation status		*p*-value [1]
	Low level N (%)	High level N (%)	
Age			
<68 years	68 (49.3)	88 (53.3)	0.48
≥68 years	70 (50.7)	77 (46.7)	
Gender			
Women	42 (30.4)	51 (30.9)	0.93
Men	96 (69.6)	114 (69.1)	
Socio-economic status [2], n: (%)			0.86
Upper	24 (17.4)	34 (20.6)	
Upper middle	32 (23.2)	31 (18.8)	
Lower middle	27 (19.6)	34 (20.6)	
Upper lower	28 (20.3)	31 (18.8)	
Lower	27 (19.6)	35 (21.2)	
CKD [3] duration in years: mean (SD)	8.8 (9.6)	9.2 (11.6)	0.74
Stage of CKD [4]			0.86
3a	30 (21.7)	42 (25.5)	
3b	35 (25.4)	42 (25.5)	
4	34 (24.6)	40 (24.2)	
5	39 (28.3)	41 (24.8)	
Diabetes duration in years: mean (SD)	17.1 (12.0)	18.2 (11.8)	0.40
Body mass index: mean, n: (%)			
Underweight	1 (1.4)	1 (1.2)	0.60
Health weight	17 (24.3)	15 (17.4)	
Overweight	21 (30.0)	23 (26.7)	
Obese	47 (67.1)	31 (36.0)	
Dialysis status			
Current	29 (21.0)	30 (18.2)	0.54
Predialysis	109 (79.0)	135 (81.8)	
HRQoL[5]: mean (SD)			
Symptom/problem list	72.0 (17.6)	75.5 (17.4)	0.08
Effect of kidney disease	71.0 (23.5)	74.1 (23.6)	0.27
Burden of kidney disease	55.9 (29.5)	63.3 (31.9)	0.04
Physical composite summary	34.4 (11.3)	36.0 (11.0)	0.26
Mental composite summary	45.5 (10.5)	48.3 (11.0)	0.03

Data are presented in N (%) unless otherwise indicated. [1] T-test for mean differences and chi-square test for differences in proportions; [2] Socio-economic status was estimated using the Australian Bureau of Statistics data. Postcodes were coded according to the Index of Relative Social Disadvantage, a composite measure based on selected census variables, which include income, educational attainment and employment status, [3] chronic kidney disease, [4] Stage of CKD-Stage 5 CKD included patients on dialysis (n=59) and not on dialysis (n=21) [5] Health related quality of life

Table 2: Univariable and multivariable regression model for factors associated with low activation in the study population

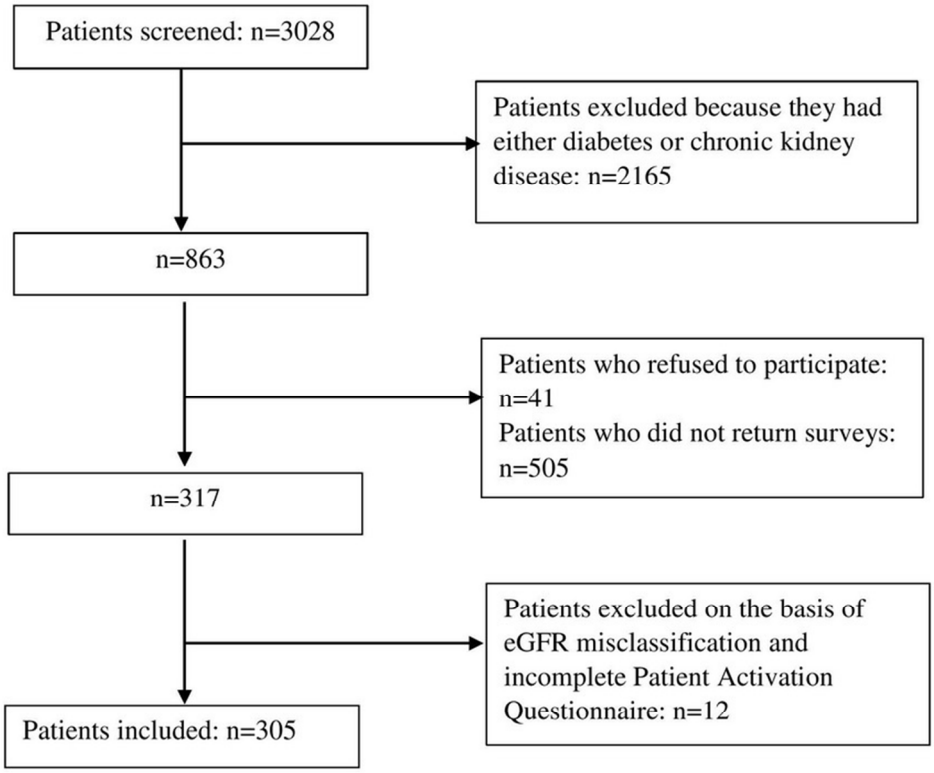
Variables	Univariable B (95% CI)	Multivariable B (95% CI)
Age	-0.05 (-0.22 to 0.11)	-0.18 (-0.35 to -0.01)*
Gender		
Men	Ref	Ref
Women	-0.79 (-4.59 to 3.02)	-
Health related quality of life		
Symptom problem list	0.15 (0.05 to 0.25)**	-
Effects of kidney disease	0.09 (0.02 to 0.17)*	-
Burden of kidney disease	0.11 (0.05 to 0.16)***	0.11 (0.05 to 0.17)***
Physical composite summary	0.17 (0.01 to 0.33)*	-
Mental composite summary	0.26 (0.09 to 0.42)**	-
Duration of diabetes	-0.02 (-0.17 to 0.13)	-
Duration of kidney disease	0.07 (-0.11 to 0.25)	-
eGFR [1]	0.11 (0.00 to 0.21)*	0.01 (-0.12 to 0.15)
Body mass index		
Healthy weight [2]	Ref	Ref
Overweight	-2.78 (-7.75 to 2.20)	-
Obese	1.98)-2.03 to 5.99)	-
Socioeconomic status [3]		
Lower	Ref	Ref
Lower middle	-0.31 (-4.75 to 4.12)	-
Upper lower	-1.42 (-5.80 to 2.95)	-
Upper middle	-0.95 (-5.27 to 3.38))	-
Upper	3.17 (-1.28 7.62)	-
Self-care composite score	0.21 (0.06 to 0.37)**	0.18 (0.02 to 0.35)*

*p<0.05; **p<0.01, ***p<0.001; 1-per 1ml/min increase in eGFR; 2-due to small numbers of underweight patients (N=2), the underweight group was combined with the health weight group for this analysis; 3-Socio-economic status was estimated using the Australian Bureau of Statistics data. Postcodes were coded according to the Index of Relative Social Disadvantage (IRSD), a composite measure based on selected census variables, which include income, educational attainment and employment status.

Figure 1: Patient inclusion flow diagram

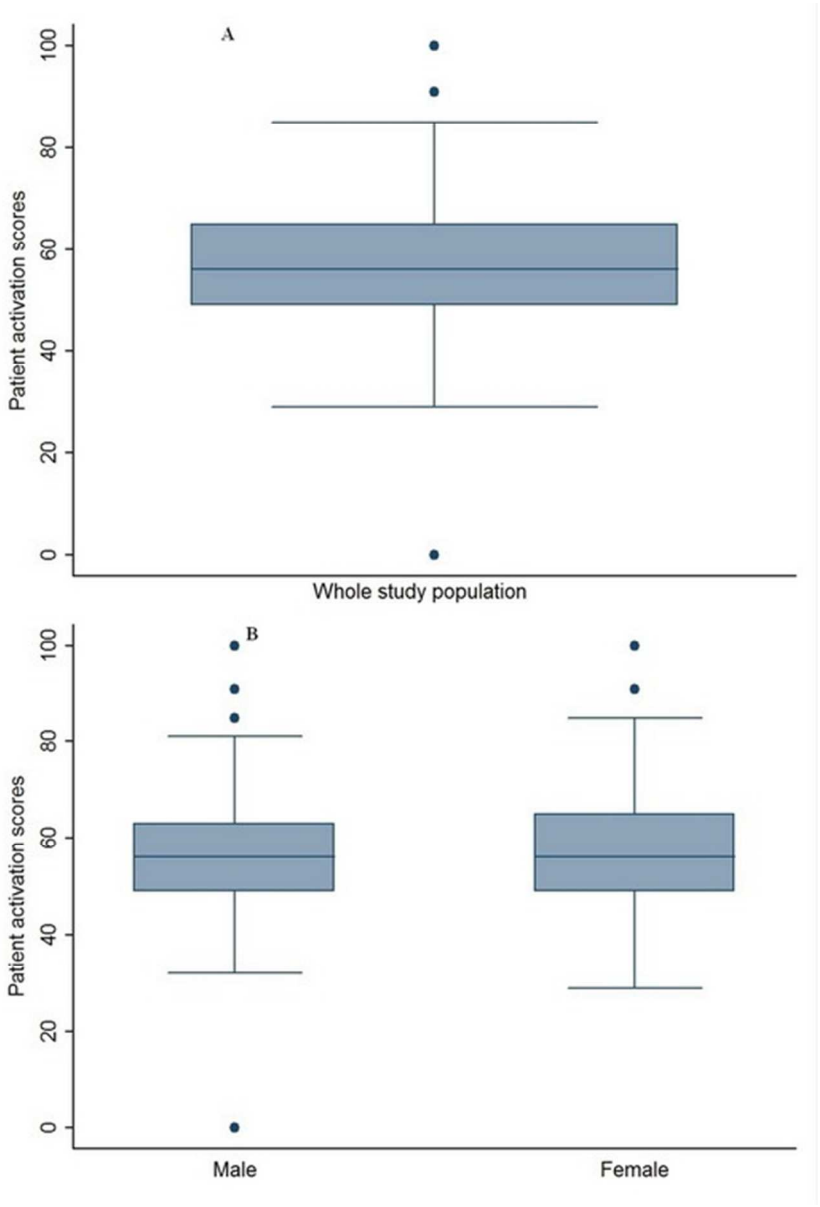
Figure 2: Patient activation. Distribution of patient activation from (A) the study population (mean 57.6, SD 15.5) and (B) men (mean 57.4, SD 16.0) and women patients (mean 58.1, SD 14.4)

Figure 3: Distribution of participants across the four levels of patient activation. Level 1 (score of 0.0–47.0) indicates that a person may not yet understand that their role as a patient is important. Level 2 (47.1– 55.1) indicates that a person lacks the confidence and knowledge to take action. Level 3 (55.2– 67) indicates that a person is beginning to take action and level 4 (67.1–100) indicates that a person is proactive about health and engages in many recommended health behaviors



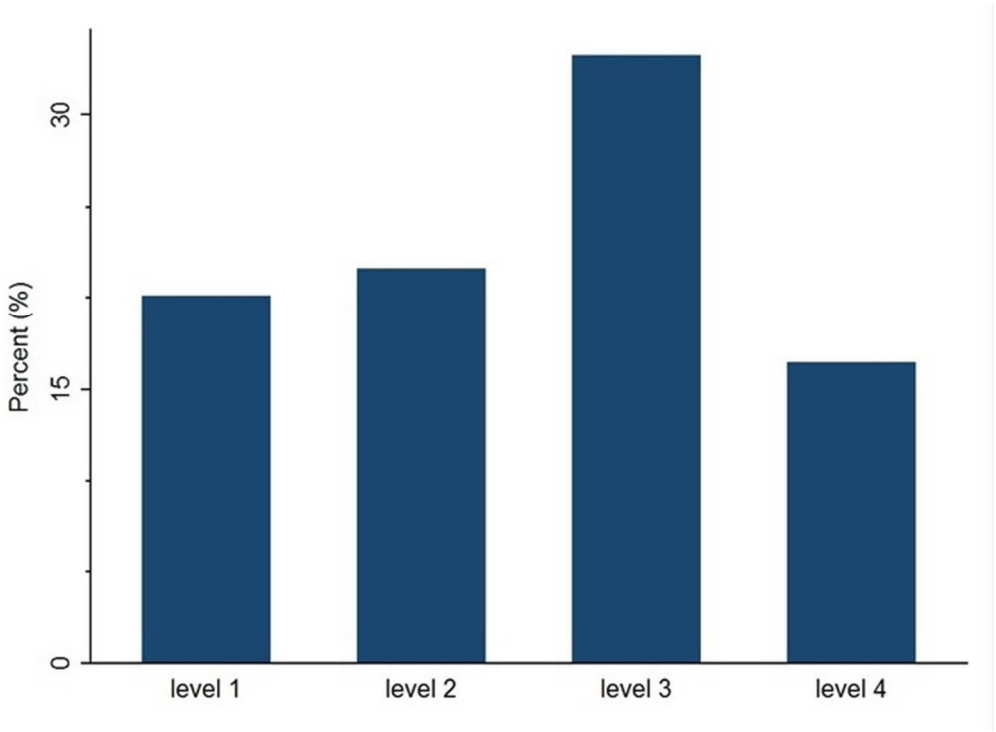
Patient inclusion flow diagram

76x64mm (300 x 300 DPI)



Patient activation. Distribution of patient activation from (A) the study population (mean 57.6, SD 15.5) and (B) men (mean 57.4, SD 16.0) and women patients (mean 58.1, SD 14.4)

43x63mm (300 x 300 DPI)



Distribution of participants across the four levels of patient activation. Level 1 (score of 0.0–47.0) indicates that a person may not yet understand that their role as a patient is important. Level 2 (47.1– 55.1) indicates that a person lacks the confidence and knowledge to take action. Level 3 (55.2– 67) indicates that a person is beginning to take action and level 4 (67.1–100) indicates that a person is proactive about health and engages in many recommended health behaviors

57x41mm (300 x 300 DPI)

S1: Characteristics of patients who did and did not participate in the study at one hospital site

	Responders	**Non-responders**	**p-value**
Patient numbers (n)	127	243	
Age (SD)	66.6 (10.8)	68.9 (11.9)	0.06
Gender (Female)	30.7	39.5	0.10
CKD stage (KDOQI %)			
3	34.2	40.9	
4	25.2	25.5	
5	33.9	40.3	0.37

KDOQI-Kidney Disease Outcomes Quality Initiative classification of stages of chronic kidney disease

S2: Univariable and multivariable regression model for factors associated with low activation in men with diabetes and chronic kidney disease

Variables	Univariable B (95% CI)	Multivariable B (95% CI)
Age	-0.11 (-0.32 to 0.12)	-
Health related quality of life		
Symptom problem list	0.12 (0.04 to 0.25)*	-
Effects of kidney disease	0.04 (-0.05 to 0.13)	-
Burden of kidney disease	0.08 (0.01 to 0.15)*	-
Physical composite summary	0.06 (-0.15 to 0.26)	-
Mental composite summary	0.23 (0.03 to 0.43)*	0.23 (0.02 to 0.44)*
Duration of diabetes	0.01 (-0.17 to 0.20)	-
Duration of kidney disease	0.10 (-0.12 to 0.16)	-
eGFR	0.03 (-0.12 to 0.16)	-
Body mass index		
Healthy weight [1]	Ref	Ref
Overweight	-5.08 (-10.96 to 0.80)	-
Obese	2.87 (-2.08 to 7.81)	-
Socioeconomic status [2]		
Lower	Ref	Ref
Lower middle	0.41 (-5.04 to 5.85)	-
Upper lower	-0.63 (-5.98 to 4.73)	-
Upper middle	-2.23 (-7.37 to 2.92)	-
Upper	4.65 (-1.04 to 10.33)*	-
Self-care composite score	0.21 (0.01 to 0.40)*	-

*p<0.05; **p<0.01, ***p<0.001; 1-due to small numbers of underweight patients (N=2), the underweight group was combined with the healthy weight group for this analysis; 2-Socio-economic status was estimated using the Australian Bureau of Statistics data. Postcodes were coded according to the Index of Relative Social Disadvantage, a composite measure based on selected census variables, which include income, educational attainment and employment status.

S3: Univariable and multivariable regression model for factors associated with low activation in women with diabetes and chronic kidney disease

Variables	Univariable B (95% CI)	Multivariable B (95% CI)
Age	0.02 (-0.21 to 0.26)	-
Health related quality of life		
Symptom problem list	0.21 (0.06 to 0.36)**	0.2 (0.05 to 0.35)**
Effects of kidney disease	0.21 (0.09 to 0.33)**	-
Burden of kidney disease	0.18 (0.09 to 0.27)***	-
Physical composite summary	0.45 (0.19 to 0.71)**	-
Mental composite summary	0.33 (0.05 to 0.60)*	-
Duration of diabetes	-0.09 (-0.35 to 0.17)	-
Duration of kidney disease	0.02 (-0.31 to 0.27)	-
eGFR	0.27 (0.10 to 0.43)**	0.27 (0.11 to 0.44)**
Body mass index		
Healthy weight [1]	Ref	Ref
Overweight	4.85 (-4.75 to 14.40)	-
Obese	-0.66 (-7.00 to 6.87)	-
Socioeconomic status [2]		
Lower	Ref	Ref
Lower middle	-1.99 (-9.71 to 5.73)	-
Upper lower	-3.33 (-11.03 to 4.38)	-
Upper middle	-3.40 (-4.93 to 11.73)	-
Upper	0.27 (-6.88 to 7.42)	-
Self-care composite score	0.23 (-0.06 to 0.53	-

p<0.05; **p<0.01, ***p<0.001; 1-due to small numbers of underweight patients (N=2), the underweight group was combined with the healthy weight group for this analysis; 2-Socio-economic status was estimated using the Australian Bureau of Statistics data. Postcodes were coded according to the Index of Relative Social Disadvantage, a composite measure based on selected census variables, which include income, educational attainment and employment status.

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Hospital ID: Site Staff ID: Participant ID:

DRP: Diabetes Renal Project - (Patient Survey - Health Experiences)

Thank-you for participating in this large multi-centre research project, called the Diabetes Renal Project (DRP). This National Health and Medical Research Council (NHMRC) partnership project is being conducted by Monash University, in partnership with Monash Health, Alfred Health, Royal North Shore Hospital, Concord Repatriation General Hospital, The George Institute for Global Health, Diabetes Australia, and Kidney Health Australia.

INSTRUCTIONS

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If you make a **mistake when writing**, cross it out with one thick line and write your correct answer above the box.

To answer a multiple choice question place a **CROSS INSIDE** the box like this: ☒

If you make a **mistake**, place a diagonal line through the incorrect answer like this: ☒ and then put a cross in the box of your preferred response.

Write dates using leading zeros (e.g. **6th April 2011 = 06/04/2011**)

DO NOT USE liquid paper to correct mistakes.

AVOID folding the form.

Please complete every page of the questionnaire. Sometimes questions may seem very similar or repetitious but they are all a little different, so please answer each question.

THANK YOU

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Hospital ID: Site Staff ID: Participant ID:

Date day / month / year

Part 1: Health Indicators (Patient Survey)

Section 1: General Information

1. Age (years)

2. Country of birth _____

3. Main language spoken at home?

☐ English ☐ Italian ☐ Spanish ☐ Greek

☐ Arabic ☐ Vietnamese ☐ Cantonese ☐ Hindi

☐ Mandarin ☐ Other, (please specify) → _____

Section 2: Diabetes

4. What type of diabetes do you have? ☐ Type 1 ☐ Type 2 ☐ Unsure ☐ Other

5. How many years have you had diabetes? *years* *months*

6. How do you manage your diabetes? *(select all that apply)*

☐ Diet and lifestyle only ☐ Insulin injections (3 or fewer per day)

☐ Tablets to lower blood glucose ☐ Insulin injections (4 or more per day)

☐ Byetta injections (2 per day) ☐ Insulin pump therapy

☐ Other (please specify) → _____

7. If you use insulin how confident are you in self- adjusting your insulin dose? *(select one option)*

Not at all confident ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 *Extremely Confident*

Section 3: Kidney Disease

8. How many years have you had kidney disease? *years* *months*

9. Did you develop kidney disease as a result of your diabetes? ☐ No ☐ Yes ☐ Unsure

Section 4: Medication

10. Who explains your medications to you? *(select all that apply)*

☐ GP ☐ Diabetes nurse

☐ GP Practice Nurse ☐ Kidney doctor at a public hospital clinic

☐ Private kidney specialist ☐ Diabetes doctor at a public hospital clinic

☐ Kidney nurse ☐ Pharmacist

☐ Private endocrinologist/diabetes specialist

☐ Other (please specify) → _____

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Hospital ID: Site Staff ID: Participant ID:

Section 4: Medication (cont)

11. Which health professional(s) do you see to manage your diabetes and kidney disease? *(select all that apply)*

- ☐ GP
- ☐ GP Practice Nurse
- ☐ Private kidney specialist
- ☐ Kidney nurse
- ☐ Private endocrinologist/diabetes specialist
- ☐ Diabetes nurse
- ☐ Kidney doctor at a public hospital clinic
- ☐ Diabetes doctor at a public hospital clinic
- ☐ Dietitian
- ☐ Podiatrist
- ☐ Optometrist
- ☐ Ophthalmologist
- ☐ Other (please specify) → _____

12. Please record the last time you saw the following health professionals. (S*elect the appropriate frequency for each professional)*

		0-3 months ago	4-6 months ago	7-12 months ago	Over 12 months ago	Never	Uncertain
a.	Endocrinologist (diabetes doctor)	☐	☐	☐	☐	☐	☐
b.	Nephrologist (kidney doctor)	☐	☐	☐	☐	☐	☐
c.	Diabetes Nurse Educator	☐	☐	☐	☐	☐	☐
d.	Kidney Nurse Practitioner	☐	☐	☐	☐	☐	☐
e.	Optometrist	☐	☐	☐	☐	☐	☐
f.	Ophthalmologist	☐	☐	☐	☐	☐	☐
g.	Podiatrist	☐	☐	☐	☐	☐	☐
h.	Dentist	☐	☐	☐	☐	☐	☐
i.	Dietitian	☐	☐	☐	☐	☐	☐
j.	Social Worker	☐	☐	☐	☐	☐	☐

13. If you run out of medication what would you do? (S*elect all that apply)*

- ☐ Obtain a supply from my local pharmacy, even if I didn't have a prescription
- ☐ Obtain a prescription from my GP then have it filled at my local pharmacy
- ☐ Wait until I next saw a doctor to obtain another prescription
- ☐ I never run out because I always ensure I have a spare supply

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Hospital ID: Site Staff ID: Participant ID:

Section 5. Barriers and support

14. Barriers causing difficulty in caring for your diabetes and kidney disease *(Mark disagree or somewhat disagree or somewhat agree or agree to each listed barrier. Please choose only one option per barrier).*

	Disagree	Somewhat disagree	Somewhat agree	Agree
a. My diabetes and kidney specialist does not spend enough time with me	☐	☐	☐	☐
b. My diabetes and kidney specialist does not provide me with enough information/education about my diabetes and kidney disease	☐	☐	☐	☐
c. I am often seen by a different doctor each time I attend my diabetes or kidney disease appointment	☐	☐	☐	☐
d. My specialists give me conflicting advice	☐	☐	☐	☐
e. I do not have a good relationship with my specialist or other specialist health service staff	☐	☐	☐	☐
f. Specialist health service staff are not caring, polite and helpful	☐	☐	☐	☐
g. My specialists do not communicate well with my GP	☐	☐	☐	☐
h. My specialists don't communicate well with each other	☐	☐	☐	☐
i. I do not have a good GP	☐	☐	☐	☐
j. I need more education and understanding of my diabetes	☐	☐	☐	☐
k. I need more education and understanding of my kidney disease	☐	☐	☐	☐
l. The information provided by my doctors or health professionals is hard to understand because English is not my first language or the information is not culturally relevant	☐	☐	☐	☐
m. The information provided by my doctors or health professionals is too complicated	☐	☐	☐	☐
n. It is difficult to obtain medical support and advice for my diabetes when I need it	☐	☐	☐	☐
o. It is difficult to obtain medical support and advice for my kidney disease when I need it	☐	☐	☐	☐
p. I have had an unsatisfactory prior experience with a diabetes or kidney health service/specialist	☐	☐	☐	☐
q. I am unable to afford the cost of attending appointments or buying medication for my diabetes	☐	☐	☐	☐
r. I have trouble adjusting to the impact that diabetes and kidney disease has made on my life and/or that of my family and friends	☐	☐	☐	☐
s. My diabetes and kidney disease makes me feel very unwell	☐	☐	☐	☐
t. My other illnesses affect my ability to look after my diabetes and kidney disease	☐	☐	☐	☐

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Section 5: Barriers and support (cont)

	Disagree	Somewhat disagree	Somewhat agree	Agree
u. I have many other stressors in my life, and taking care of my diabetes and kidney disease is not a high priority	☐	☐	☐	☐
v. My job makes it difficult to take care of my diabetes and kidney disease well	☐	☐	☐	☐
w. My mood (e.g. feeling down, worried, frustrated) gets in the way of me looking after my diabetes and kidney disease	☐	☐	☐	☐
x. I do not feel motivated enough to look after my diabetes and kidney disease well	☐	☐	☐	☐
y. I have trouble maintaining the right diet or fluid restriction for my diabetes and kidney disease	☐	☐	☐	☐
z. I have difficulty knowing what I can eat/drink, for my diabetes and kidney disease	☐	☐	☐	☐
aa. I experience unpleasant side-effects from my medication	☐	☐	☐	☐
bb. I do not receive support from my family	☐	☐	☐	☐
cc. I do not receive support from my friends	☐	☐	☐	☐
dd. I find it difficult to get services for home-help	☐	☐	☐	☐

ee. Please list any additional problems: _____

_____

Section 6: Diabetes Service and Kidney Service

15. Are you registered with the National Diabetes Service Scheme (NDSS)? *This service supports people living with diabetes by providing subsidised blood glucose strips and free insulin pen needles/syringes. It is not the same as being a member of Diabetes Australia.* ☐ No ☐ Yes

16. Do you have difficulty in accessing a diabetes service?

☐ No → Skip to Q 17

☐ Yes → **16.1. Why is it difficult for you to access a diabetes service?** *(select all that apply)*

☐ No private transport e.g. car/ driver
☐ Parking (e.g. cost, locality to the clinic)
☐ Disability
☐ Cost (e.g. appointments, prescription costs)
☐ Time of appointment (e.g. during work hours)
☐ Location of the service (e.g. distance from home)
☐ Time spent each week at dialysis
☐ I have too many appointments
☐ Long waiting times before I get an appointment
☐ Long waiting times in the waiting room before I see a doctor
☐ I don't have a problem with accessing a service
☐ Other (please specify) → _____

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Hospital ID: Site Staff ID: Participant ID:

Section 6: Diabetes Service and Kidney Service (cont)

17. How satisfied are you with the care provided by your diabetes service? *(select one option)*

Not at all satisfied ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 *Extremely Satisfied*

18. Do you have difficulty in accessing a kidney service?

☐ No → Skip to Q 19

☐ Yes → **18.1. Why is it difficult for you to access a kidney service?** *(select all that apply)*

- ☐ No private transport e.g. car/ driver
- ☐ Parking (e.g. cost, locality to the clinic)
- ☐ Disability
- ☐ Cost (e.g. appointments, prescription costs)
- ☐ Time of appointment (e.g. during work hours)
- ☐ Location of the service (e.g. distance from home)
- ☐ Other (please specify) →
- ☐ Time spent each week at dialysis
- ☐ I have too many appointments
- ☐ Long waiting times before I get an appointment
- ☐ Long waiting times in the waiting room before I see a doctor
- ☐ I don't have a problem with accessing a service

19. How satisfied are you with the care provided by your kidney service? *(select one option)*

Not at all satisfied ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 *Extremely Satisfied*

20. An ideal health service to look after my diabetes and kidney disease would include: *(please cross either no or yes in the table below)*

a. Regular contact with a case manager, nurse or doctor who knows my entire medical history and who will help me coordinate the management of my health	☐ No	☐ Yes
b. Education sessions to help me manage my diabetes, including information about correct food choices and what support is available	☐ No	☐ Yes
c. Education sessions to help me manage my kidney disease, including information about correct food choices and what support is available	☐ No	☐ Yes
d. Education sessions for my family so that they can understand my condition	☐ No	☐ Yes
e. Education sessions targeted to the public/community about diabetes and kidney disease	☐ No	☐ Yes
f. Education handouts that are culturally relevant, in my native language, easy to understand, and in an appropriate format (e.g. DVD)	☐ No	☐ Yes
g. Seeing the same doctor or health professional when I attend my diabetes and kidney disease appointments	☐ No	☐ Yes
h. All my doctors giving me the same information/advice, instead of conflicting information/advice	☐ No	☐ Yes
i. Good communication between my doctors	☐ No	☐ Yes
j. Centralised Electronic health medical records with investigation results, which all my doctors can access	☐ No	☐ Yes
k. Friendly, caring, supportive and knowledgeable staff and medical professionals	☐ No	☐ Yes

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Hospital ID: Site Staff ID: Participant ID:

Section 6: Diabetes Service and Kidney Service (cont)

l. A combined multidisciplinary clinic with both diabetes and kidney doctors, as well as other health staff (such as dietitian, nurse educators, podiatrists etc) in the one place	☐ No	☐ Yes
m. Shorter waiting times in the waiting room	☐ No	☐ Yes
n. Routine access to a psychologist for emotional support	☐ No	☐ Yes
o. Routine access to a dietitian	☐ No	☐ Yes
p. Routine access to a podiatrist	☐ No	☐ Yes
q. Routine access to an eye doctor	☐ No	☐ Yes
r. Routine access to a diabetes nurse educator	☐ No	☐ Yes
s. Routine access to a kidney nurse	☐ No	☐ Yes
t. Routine access to a pharmacist	☐ No	☐ Yes
u. Routine access to a social worker	☐ No	☐ Yes
v. Routine access to an occupational therapist	☐ No	☐ Yes
w.Routine review by doctors and health professionals for my diabetes and kidney disease (e.g. diabetes doctor, dietitian, podiatrist) while I am on dialysis	☐ No	☐ Yes
x. Appointment reminders (e.g. phone call/text message/email) prior to my appointment	☐ No	☐ Yes
y. Incentives to staff members to provide good patient service (e.g. Monthly prize)	☐ No	☐ Yes
z. Debriefing groups and education sessions for staff members to improve patient care	☐ No	☐ Yes
aa. Affordable parking close to clinic/dialysis	☐ No	☐ Yes
bb. Diabetes and renal services being offered in my local community, rather than primarily based in the hospital	☐ No	☐ Yes
cc. 24 hour hotline to staff in case I need advice or assistance	☐ No	☐ Yes

Section 7: Summary of Diabetes Self Care Activities for Diabetes and Kidney Disease

Please recall the last 7 days that you were well when answering the following questions. (Please select one response per question).

Diet

21. How many of the last 7 days have you followed a healthy eating plan?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

22. Over the past month how many days per week have you followed your eating plan?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

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Hospital ID: Site Staff ID: Participant ID:

Section 7: Summary of Diabetes Self Care Activities for Diabetes and Kidney Disease (cont)

23. On how many of the last 7 days did you eat five or more servings of fruit?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

24. On how many of the last 7 days did you eat high fat foods such as red meat or full dairy products?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

Excercise

25. On how many of the last 7 days did you participate in at least 30min of exercise?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

26. On how many of the last 7 days did you participate in a specific exercise session?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

Blood Sugar Testing

27. On how many of the last 7 days did you test your blood sugar?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

28. On how many of the last 7 days did you test your blood sugar the number of times recommended by your health care provider?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

Foot Care

29. On how many of the last 7 days did you check your feet?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

30. On how many of the last 7 days did you inspect the inside of your shoes?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

Smoking

31. Have you smoked or taken a puff of a cigarette in the last 7 days?

☐ No → Skip to Q 32

☐ Yes → **31.1 How many cigarettes did you smoke on an average day?** ☐☐☐

Medications

32. On how many of the last 7 days did you take your recommended diabetes medication?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

33. On how many of the last 7 days did you take your recommended insulin injections?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

34. On how many of the last 7 days did you take your recommended number of diabetes pills?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

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Hospital ID: Site Staff ID: Participant ID:

DRP: Diabetes Renal Project (Doctors Survey - Health Indicators)

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THANK YOU

27311

Hospital ID: Site Staff ID: Participant ID:

Date day / month / year

Health Indicators (Doctors Survey)

Section 1: Demographic of Patient Participant

1. Age *(years)*

2. Gender ☐ Male ☐ Female

3. Participant Post-code

4. Aboriginal background ☐ No ☐ Yes

5.Torres Strait Islander background ☐ No ☐ Yes

6. Maori/Pacific Strait Islander background ☐ No ☐ Yes

7. Is the participant a current smoker ?

☐ No → Skip to Q 8

☐ Yes → **7.1. Average number of cigarettes smoked per day?**

8. Has the participant previously smoked ?

☐ No → Skip to Q 9

☐ Yes → **8.1. Average number of cigarettes smoked per day?**

9. Does the participant currently drink alcohol?

☐ No → Skip to Q 10

☐ Yes → **9.1. Average number of standard drinks per week?**

Section 2: Examination Findings

Please complete with the most recent examination findings and date of examination

10. Blood Pressure - *(the average of 3 readings measured after 5 minutes sitting)*

/ mmHg → **10.1** day / month / year

11. Heart Rate Bpm → **11.1** day / month / year

12. Weight . Kg → **12.1** day / month / year

13. Height . Metres → **13.1** day / month / year

At the most recent examination, does the participant have the following conditions:

14a. New loss of vibratory sensation (both feet)

☐ No ☐ Yes → Date of examination **14a.1** day / month / year

☐ Not examined/unknown

14b. New loss of ankle reflexes (both legs)

☐ No ☐ Yes → Date of examination **14b.1** day / month / year

☐ Not examined/unknown

14c. New loss of light touch (eg. loss of pressure sensation with 10gm force monofilament)

☐ No ☐ Yes → Date of examination **14c.1** day / month / year

☐ Not examined/unknown

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Hospital ID: ☐ Site Staff ID: ☐☐☐☐☐ Participant ID: ☐☐☐☐

Section 2: Examination Findings (cont)

15. Foot ulcers

☐ No ☐ Yes → Date of examination **15.1** ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year)

☐ Not examined/unknown

16. Foot deformity

☐ No ☐ Yes → Date of examination **16.1** ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year)

☐ Not examined/unknown

Section 3: Medical History

17. Diabetes Type ☐ Type 1 ☐ Type 2 **18. Duration of diabetes** ☐☐ *years* ☐☐ *months*

OR ☐ Unknown/not documented

Has the participant experienced any of the following complications/comorbidities?

19. Ischemic Heart Disease?	☐ No	☐ Yes	**23. Peripheral Neuropathy?**	☐ No	☐ Yes
20. Stroke?	☐ No	☐ Yes	**24. Diabetic Nephropathy?**	☐ No	☐ Yes
21. Peripheral Vascular disease?	☐ No	☐ Yes	**25. Hypertension**	☐ No	☐ Yes
22. Diabetic Retinopathy?	☐ No	☐ Yes	**26. Dyslipidemia**	☐ No	☐ Yes

27. Does the participant have a family history of heart disease? ☐ No ☐ Yes

OR ☐ Unknown/not documented

---

28. Duration of nephrological care ☐☐ *years* ☐☐ *months* **OR** ☐ Unknown/not documented

29. Kidney disease stage *(select one option)* ☐ Stage 3a ☐ Stage 3b ☐ Stage 4 ☐ Stage 5

30. Is the patient currently on dialysis?

☐ No → Skip to Q 31

☐ Yes → **30.1 Haemodialysis** ☐ No ☐ Yes → **30.2** Number of months on dialysis ☐☐☐

30.3 Peritoneal ☐ No ☐ Yes → **30.4** Number of months on dialysis ☐☐☐

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Hospital ID: Site Staff ID: Participant ID:

Section 3: Medical History (cont)

31. Prior to their current dialysis, has the patient been on any other form of dialysis?

☐ No → Skip to Q 32

☐ Yes→ **31.1 Haemodialysis?** ☐ No ☐ Yes

Date commenced **31.2** day / month / year

Date ceased **31.3** day / month / year

31.4 Peritoneal dialysis? ☐ No ☐ Yes

Date commenced **31.5** day / month / year

Date ceased **31.6** day / month / year

32. Has the patient had a kidney transplant?

☐ No → Skip to Q 33

☐ Yes→ **32.1 Date of transplant** day / month / year

OR ☐ Unknown/not documented

Section 4: Medical Care of Diabetes and Chronic Kidney Disease

33. How often does the participant monitor his/her diabetes with a blood glucose monitor? *(select one option)*

☐ ≥ 3 times per day ☐ Once per day (daily) ☐ Once per week (weekly) ☐ Uncertain

☐ 2 times per day ☐ A few times per week ☐ Rarely ☐ Not documented

34. Please indicate when the participant was last referred/seen by the following health professionals. *(Select the appropriate response for each health professional).*

	Not referred/reviewed by this health professional	3 months or less	4-12 months ago	13-24 months ago	As required	Uncertain
a. Endocrinologist	☐	☐	☐	☐	☐	☐
b. Nephrologist	☐	☐	☐	☐	☐	☐
c. Diabetes Nurse Educator	☐	☐	☐	☐	☐	☐
d. Renal Nurse Practitioner	☐	☐	☐	☐	☐	☐
e. Optometrist	☐	☐	☐	☐	☐	☐
f. Ophthalmologist	☐	☐	☐	☐	☐	☐
g. Podiatrist	☐	☐	☐	☐	☐	☐
h. Dentist	☐	☐	☐	☐	☐	☐
i. Dietician	☐	☐	☐	☐	☐	☐
j. Social Worker	☐	☐	☐	☐	☐	☐

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Hospital ID: Site Staff ID: Participant ID:

Section 5: Medications

35. Is the participant on Insulin?

☐ No → Skip to Q 36

☐ Yes→ **35.1 Is the participant on an Insulin pump?** ☐ No ☐ Yes

35.2 What type of insulin? *(select all that apply)*

☐ Long acting ☐ Short acting ☐ Rapid acting ☐ Basal

36. Is the participant on diabetes tablets?

☐ No → Skip to Q 34

☐ Yes→ **Does the participant take:**

36.1 Metformin?	☐ No	☐ Yes
36.2 Sulphonylurea?	☐ No	☐ Yes
36.3 Glitazone?	☐ No	☐ Yes
36.4 Acarbose?	☐ No	☐ Yes
36.5 Gliptin (DPP4 inhibitor)?	☐ No	☐ Yes
36.6 GLP1 agonist? (e.g exenatide or liraglutide)	☐ No	☐ Yes
36.7 SGLT2 inhibitors?	☐ No	☐ Yes

36.8 Other diabetes medication *(please list below)*

37. Other medications - is the participant taking:

37.1 ACE inhibitor?	☐ No	☐ Yes
37.2 Angiotensin2 Receptor Blocker?	☐ No	☐ Yes
37.3 Other Antihypertensives?	☐ No	☐ Yes
37.4 Statin?	☐ No	☐ Yes
37.5Fibrate?	☐ No	☐ Yes
37.6 Erythropoieting Stimulating Agent?	☐ No	☐ Yes
37.7 Phosphate binder?	☐ No	☐ Yes
37.8 Iron Supplementation (IV or Oral)?	☐ No	☐ Yes

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Hospital ID: Site Staff ID: Participant ID:

Section 6: Investigations

38. Has a HbA1c test been performed in the last 3 months? ☐ No ☐ Yes

Please record the most recent HbA1c result

38.1 HbA1c ☐☐☐ mmol/mol ***and*** **38.2** ☐☐.☐ % → **38.3** Date of test ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year)

39. Please enter details below of the most recent lipid profile results:

39.1 Total Cholesterol ☐☐.☐ mmol/L

39.2 LDL Cholesterol ☐.☐☐ mmol/L

39.3 HDL Cholesterol ☐☐.☐☐ mmol/L

39.4 Triglycerides ☐.☐☐ mmol/L

39.5 Date of test ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year)

OR ☐ Not tested

40. Please enter details below of the most recent serum biochemistry profile results:

40.1 Potassium ☐.☐ mmol/L

40.2 Creatinine ☐☐☐☐ µmol/L

40.3 Calcium ☐.☐☐ mmol/L

40.4 Phosphate ☐.☐☐ mmol/L

40.5 Parathyroid hormone (PTH) ☐☐☐.☐
(result within last 6 months)

40.5.1 Units ☐ pmol/L ☐ ng/L

OR ☐ Not done within the past 6 months

40.6 eGFR ☐☐☐ mL/min per 1.73m^2

40.7 Albumin ☐☐☐ g/L

40.8 Date of test ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year)

(For PTH, please record result from within the past 6 months of this date)

OR ☐ Not tested

41. Please record the most recent spot urine albumin / creatinine ratio (ACR):

☐☐☐☐.☐☐ mg/mmol **40.1 Date of test** ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year) **OR** ☐ Not tested

42. If you have used another method to measure microalbumin / proteinuria please record details below:

☐☐☐☐.☐☐ **42.1 Units** ☐ mg/L ☐ mg/24hr ☐ µg/min ☐ g/mmol ☐ g/L

42.2 Date of test ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year) **OR** ☐ Not tested

43. Please enter the most recent Haemoglobin test result: ☐☐☐ g/L **43.1 Date of test** ☐☐ / ☐☐ / ☐☐☐☐ (day / month / year)

OR ☐ Not tested

The Summary of Diabetes Self- Care Activities for Diabetes and Kidney Disease

*The questions below ask you about your diabetes and kidney disease self-care activities during the past **7 days**. If you were sick during the past 7 days, please think back to the last 7 days that you were not sick.*

Diet

How many of the last SEVEN DAYS have you followed a healthful eating plan?

0 1 2 3 4 5 6 7

On average, **over the past month**, how many DAYS PER WEEK have you followed your eating plan?

0 1 2 3 4 5 6 7

On how many of the last SEVEN DAYS did you eat five or more servings of fruits and vegetables?

0 1 2 3 4 5 6 7

On how many of the last SEVEN DAYS did you eat high fat foods such as red meat or full-fat dairy products?

0 1 2 3 4 5 6 7

Exercise

On how many of the last SEVEN DAYS did you participate in at least 30 minutes of physical activity? (Total minutes of continuous activity, including walking).

0 1 2 3 4 5 6 7

On how many of the last SEVEN DAYS did you participate in a specific exercise session (such as swimming, walking, biking) other than what you do around the house or as part of your work?

0 1 2 3 4 5 6 7

Blood Sugar Testing

On how many of the last SEVEN DAYS did you test your blood sugar?

0 1 2 3 4 5 6 7

On how many of the last SEVEN DAYS did you test your blood sugar the number of times recommended by your health care provider?

0 1 2 3 4 5 6 7

Foot Care

On how many of the last SEVEN DAYS did you check your feet?

0 1 2 3 4 5 6 7

On how many of the last SEVEN DAYS did you inspect the inside of your shoes?

0 1 2 3 4 5 6 7

Smoking

Have you smoked a cigarette—even one puff—during the past SEVEN DAYS?

0. No

1. Yes.

If yes, how many cigarettes did you smoke on an average day?

Number of cigarettes: ……

Medications

On how many of the last SEVEN DAYS, did you take your recommended diabetes medication?

0 1 2 3 4 5 6 7

On how many of the last SEVEN days did you take your recommended insulin injections?

0 1 2 3 4 5 6 7

On how many of the last SEVEN days did you take your recommended number of diabetes pills?

0 1 2 3 4 5 6 7

Toobert et al. The Summary of Diabetes Self-Care Activities Measure. Diabetes Care, 23(7) July 2000: 943-950.

Your Health

– *and* –

Well-Being

Kidney Disease and Quality of Life (KDQOL™-36)

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Thank you for completing these questions!

Study of Quality of Life For Patients on Dialysis

What is the purpose of the study?

This study is being carried out in cooperation with physicians and their patients. The purpose is to assess the quality of life of patients with kidney disease.

What will I be asked to do?

For this study, we want you to complete a survey today about your health, how you feel and your background.

Confidentiality of information?

We do not ask for your name. Your answers will be combined with those of other participants in reporting the findings of the study. Any information that would permit identification of you will be regarded as strictly confidential. In addition, all information collected will be used only for purposes of the study, and will not be disclosed or released for any other purpose without your prior consent.

How will participation benefit me?

The information you provide will tell us how you feel about your care and further understanding about the effects of medical care on the health of patients. This information will help to evaluate the care delivered.

Do I have to take part?

You do not have to fill out the survey and you can refuse to answer any question. Your decision to participate will not affect your opportunity to receive care.

Your Health

This survey includes a wide variety of questions about your health and your life. We are interested in how you feel about each of these issues.

1. In general, would you say your health is: [Mark an ☒ in the one box that best describes your answer.]

Excellent	Very good	Good	Fair	Poor
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? [Mark an ☒ in a box on each line.]

	Yes, limited a lot	Yes, limited a little	No, not limited at all
2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	☐ 1	☐ 2	☐ 3
3. Climbing several flights of stairs	☐ 1	☐ 2	☐ 3

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	Yes	No
4. Accomplished less than you would like.....	☐ 1	☐ 2
5. Were limited in the kind of work or other activities	☐ 1	☐ 2

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	Yes	No
6. Accomplished less than you would like.....	☐ 1	☐ 2
7. Didn't do work or other activities as carefully as usual	☐ 1	☐ 2

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks…

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
9. Have you felt calm and peaceful?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
10. Did you have a lot of energy?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
11. Have you felt downhearted and blue?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

12. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Your Kidney Disease

How true or false is each of the following statements for you?

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
13. My kidney disease interferes too much with my life	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
14. Too much of my time is spent dealing with my kidney disease	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
15. I feel frustrated dealing with my kidney disease	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
16. I feel like a burden on my family	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

During the <u>past 4 weeks</u>, to what extent were you bothered by each of the following?

	Not at all bothered	Somewhat bothered	Moderately bothered	Very much bothered	Extremely bothered
	▼	▼	▼	▼	▼
17. Soreness in your muscles?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
18. Chest pain?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
19. Cramps?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
20. Itchy skin?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
21. Dry skin?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
22. Shortness of breath?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
23. Faintness or dizziness?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
24. Lack of appetite?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
25. Washed out or drained?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
26. Numbness in hands or feet?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
27. Nausea or upset stomach?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
28[a]. (Hemodialysis patient only) Problems with your access site?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
28[b]. (Peritoneal dialysis patient only) Problems with your catheter site?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Effects of Kidney Disease on Your Daily Life

Some people are bothered by the effects of kidney disease on their daily life, while others are not. How much does kidney disease <u>bother</u> you in each of the following areas?

	Not at all bothered	Somewhat bothered	Moderately bothered	Very much bothered	Extremely bothered
29. Fluid restriction?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
30. Dietary restriction?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
31. Your ability to work around the house?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
32. Your ability to travel?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
33. Being dependent on doctors and other medical staff?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
34. Stress or worries caused by kidney disease?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
35. Your sex life?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
36. Your personal appearance?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Thank you for completing these questions!

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Hospital ID: Site Staff ID: Participant ID:

Date ___ / ___ / ____
day month year

Patient Activation Measure (PAM) 13™ ©Insignia Health, LLC 2013

Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by crossing your answer. Your answers should be what is true for you and not just what you think others want you to say. If the statement does not apply to you, cross N/A. (Please choose only one response for each statement).

	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
1. When all is said and done, I am the person who is responsible for taking care of my health	☐	☐	☐	☐	☐
2. Taking an active role in my own health care is the most important thing that affects my health	☐	☐	☐	☐	☐
3. I am confident that I can help prevent or reduce problems associated with my health	☐	☐	☐	☐	☐
4. I know what each of my prescribed medications do	☐	☐	☐	☐	☐
5. I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself	☐	☐	☐	☐	☐
6. I am confident that I can tell a doctor concerns I have even when he or she does not ask	☐	☐	☐	☐	☐
7. I am confident that I can follow through on medical treatments I may need to do at home	☐	☐	☐	☐	☐
8. I understand my health problems and what causes them	☐	☐	☐	☐	☐
9. I know what treatments are available for my health problems	☐	☐	☐	☐	☐
10. I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising	☐	☐	☐	☐	☐
11. I know how to prevent problems with my health	☐	☐	☐	☐	☐
12. I am confident I can figure out solutions when new problems arise with my health	☐	☐	☐	☐	☐
13. I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress	☐	☐	☐	☐	☐

STROBE Statement—Checklist of items that should be included in reports of ***cross-sectional studies***

	Item No	Recommendation
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract (Page 2 and page 5)
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found (Page 2-abstract)
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported (Page 4 to 5 of the background)
Objectives	3	State specific objectives, including any prespecified hypotheses (Stated on page 5, second paragraph)
Methods		
Study design	4	Present key elements of study design early in the paper (Page 5, under methods)
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection (Page 5, under methods)
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants (Page 5, lines 18-24)
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable (Page 6 to 7)
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group (Page 6 and 7; health related quality of life and patient activation)
Bias	9	Describe any efforts to address potential sources of bias (Page 6 and 7, validated measures were used)
Study size	10	Explain how the study size was arrived at
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why (Page 7 under data analysis)
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding (Page 7 to 8)
		(*b*) Describe any methods used to examine subgroups and interactions (Page 8, lines 1 to 4)
		(*c*) Explain how missing data were addressed (Page 8, line 13-15)
		(*d*) If applicable, describe analytical methods taking account of sampling strategy (N/A)
		(*e*) Describe any sensitivity analyses
Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (Page 8, line 13)
		(b) Give reasons for non-participation at each stage
		(c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (Page 8, line 15 to 22)
		(b) Indicate number of participants with missing data for each variable of interest (Page 8, line 15 to 16)

Outcome data	15*	Report numbers of outcome events or summary measures
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (Page 9)
		(*b*) Report category boundaries when continuous variables were categorized
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period N/A
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses (Page 9, lines 14 to 22- subgroup analyses by gender)
Discussion		
Key results	18	Summarise key results with reference to study objectives (Page 10, lines 1 to 10)
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias (Page 12, lines page 12 to 16)
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence (page 10 to 11)
Generalisability	21	Discuss the generalisability (external validity) of the study results (Page 12, lines 9 to 12)
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based (Page 19, under funding)

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.