Valuing Individuals: Transforming Participation in Chronic Kidney Disease

Patient Activation Measure - Patient Reported Outcome Measure Report

Cohort 1

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Contents

Executive Summary

The Transforming Participation in CKD Programme (TP-CKD) in collaboration with NHS England implemented Patient Activation and Patient Reported Outcome Measures across 10 renal units in England.

This report presents data collected at the end of phase 1 of the TP-CKD Programme from these 10 renal units. Phase 1 of the programme is testing whether it is possible to routinely gather a patient's level of knowledge, skill and confidence (Patient Activation Measure) and quality of life (Patient Reported Outcome Measure) using data collection methods.

The data collection from this survey provides novel information on patients on renal replacement therapy (RRT) and pre-dialysis patients with CKD in England and for the first time patient activation, symptoms and overall health can be evaluated and benchmarks established.

Key messages

1. Many people living with CKD completed the survey, with more than half of them doing it themselves, without needing help from others. This is a promising starting point for using the survey on a wider scale.
2. One in three patients reported feeling overwhelmed by their illness, and felt that their doctor made the decisions about their health. At the same time, a similar proportion said that they had the knowledge, skills and confidence to be part of their health care team.
3. Many patients felt they lacked the confidence to work out solutions when new health problems arose and did not feel able to maintain lifestyle changes.
4. More than half of all patients who completed the survey reported being bothered by lack of energy. Poor mobility, pain and difficulty sleeping were also very common.
5. Half of all patients had at least moderate problems with mobility and with carrying out their daily activities.

Introduction

The NHS Five Year Forward View [1] acknowledges the need to support people to manage their health and care. The Wanless report [2] comments that costs will be unsustainable unless radical reform takes place within the NHS with patients enabled to take more responsibility for their care.

The primary aim of the TP-CKD programme is to empower patients to create partnerships which support them to take greater control of their health and wellbeing, leading to better holistic outcomes for the individual. An empowered or 'activated patient' is one who has been supported sufficiently to develop the knowledge, skills and confidence to make informed and healthy choices about their health and care which are right for them, and who then uses services appropriately to support these choices. Furthermore, by gaining knowledge, skills and confidence the patient is more able to take responsibility for decisions about their healthcare in partnership with the health care team and so become increasingly independent whilst improving their overall wellbeing. Highly activated patients are more likely to adopt healthy behaviour, to have better clinical outcomes and lower rates of hospitalisation, and to report higher levels of satisfaction with services.

Patients with low activation levels are more likely to attend accident and emergency departments, to be hospitalised or to be re-admitted to hospital after being discharged. This is likely to lead to higher health care costs [3, 4].

Methods

The TP-CKD measurement work-stream developed a tool known as 'Your Health Survey' using previously validated surveys comprising (see appendix 1):

- 5 questions on overall health (EQ-5D-5L) [5]
- 17 questions on symptoms (iPOS-S renal)
- 13 questions on the ability of the patient to manage their health (Patient Activation Measure (PAM))

The PAM is calculated as a score which corresponds to a PAM level and PAM levels are described in table 1.

Table 1 Description of PAM levels [6]

Level 1	Disengaged and overwhelmed. Individuals are passive and lack self-confidence, knowledge is low, goal-orientation is weak and adherence is low. Their perspective: my doctor is in charge of my health
Level 2	Becoming aware but still struggling. Individuals have some knowledge but large gaps remain. They believe health is largely out of their control, but can set simple goals. Their perspective: I could be doing more.
Level 3	Taking action. Individuals have the key facts and are building self-management skills. They strive for best practise behaviours and are goal orientated. Their perspective: I'm part of my health care team.
Level 4	Maintaining behaviours and pushing further. Individuals have adopted new behaviours but may struggle in times of stress and change. Maintaining a healthy lifestyle is a key focus. Their perspective: I'm my own advocate.

Any comparison of results between renal centres has to be carefully interpreted as case-mix may be very different in renal centres taking part in the cohort 1 pilot study and the group of patients who completed the survey in each renal centre may not be representative of patients overall in that centre.

The PAM score is on a 100 point scale. Research has shown that each point increase in the PAM score correlates to a 2% decrease in hospitalisation [6] and it is therefore important to report the PAM score in addition to the PAM level. The Kruskal-Wallis test was used to test for differences in the median PAM activation score between categories.

As part of the TP-CKD programme 10 of the 52 adult renal units in England participated in the implementation of 'Your Health Survey' to measure patient activation, disease symptoms and quality of life outcomes. Each unit used a different approach to implementation resulting in survey returns across the whole patient pathway.

The survey was handed out to patients as a paper copy by patient volunteers, nursing and medical staff who had previously attended an initiation event and was supported by information such as leaflets and posters.

Completed surveys were returned to the UK Renal Registry (UKRR) and scanned into a database.

The EQ-5D-5L questions use a scale from 1 to 5 representing increasing difficulties with activities (1=I have no problems, 2=I have slight problems, 3=I have moderate problems, 4=I have severe problems, 5=I am unable to perform some activities.

The iPOS-S renal questions use scales from 0 to 4 representing increasing severity of symptoms (0=not at all, 1=slightly, 2=moderately, 3=severely, 4=overwhelmingly). For the purpose of this report the survey results were recoded to absent/mild and moderate/severe/overwhelming.

The PAM questions use scales 1 to 5 representing increasing activation (1=strongly disagree, 2=disagree, 3=agree, 4=strongly agree and 5=N/A).

Results

Patient demographics

10 renal units in England submitted data as part of phase 1 of the TP-CKD programme with 1,053 patients completing and returning the survey between March and August 2016.

The majority of patients completed the survey on their own (58.8%) with 15.2% receiving help from staff and 20.8% completing the survey with help from a friend or relative (table 2).

The majority of surveys were completed at the renal unit (61.1%), although a large proportion of surveys were completed at home (24.2%) and 10.2% of surveys were completed in a clinic setting (table 2).

Table 2 Patient demographics

Patient demographics	Number	Percentage
Assistance with survey completion		
Own	619	58.8
Staff	160	15.2
Friend/relative	219	20.8
Missing	55	5.2
All	1,053	100.0
Completion of survey		
At home	255	24.2
Renal unit	643	61.1
Clinic	107	10.2
Missing	48	4.6
All	1,053	100.0
Age distribution		
18 to 24	27	2.6
25 to 34	56	5.3
35 to 44	80	7.6
45 to 54	162	15.4
55 to 64	217	20.7
65 to 74	234	22.3
75+	274	26.1
Missing	3	0.3
All	1,053	100.0

Almost 70% of patients completing the survey were older than 55 years of age with only 2.6% completing the survey in the 18-24 age group (table 2).

Results - Patient Activation Measure (PAM)

- Thirty one percent of patient's surveyed self-assessed as being on the lowest activation level (level 1), suggesting that they feel overwhelmed and passive with no understanding of their role in taking responsibility for their own health care.
- Nineteen percent of patient's surveyed self-assessed as level 2 showing they have some knowledge and understanding about their role and responsibilities in their own healthcare but large gaps remain in skills and confidence.
- Thirty-two percent of patients surveyed self-assessed as level 3 meaning that they possess key knowledge and skills and confidence to be actively working with the health care team.
- Fifteen percent of patients self-assessed at level 4, showing they possess knowledge, skills and confidence to participate in their care, and sustain behaviours and partnerships to maintain health (see table 3).

Table 3 Patient Activation Measure

PAM level	Number	Percentage
Level 1	329	31.2
Level 2	198	18.8
Level 3	334	31.7
Level 4	160	15.2
Missing	32	3.0
All	1,053	100.0

Figure 1 shows a large variation in the median PAM score by renal centre ranging from 49 to 62 with the median PAM score for all 10 renal centres at 53.. Renal centre 7 shows the highest median PAM activation score.

Figure 1 Median PAM score by renal unit

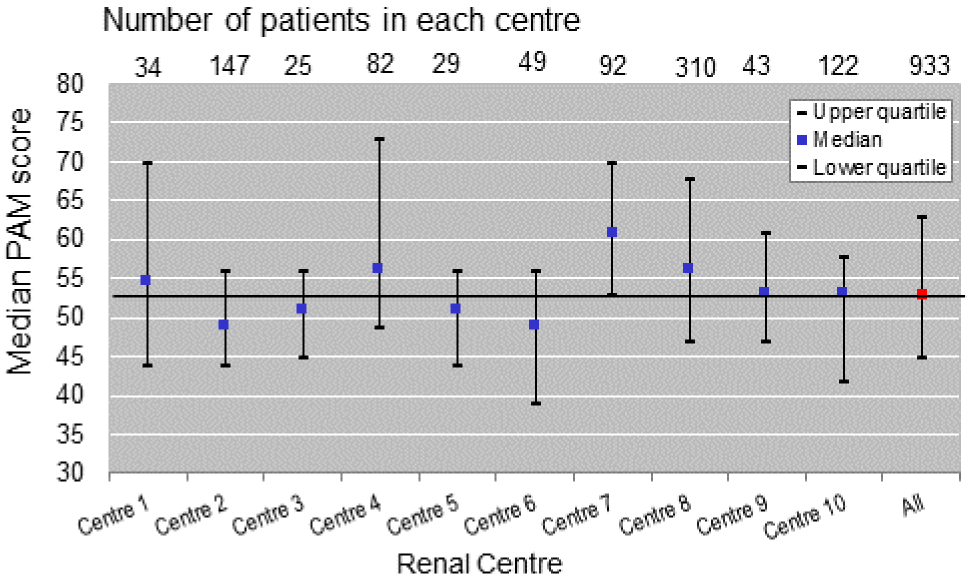


Figure 2 shows centre 7 as having the largest proportion of patients on activation level 3 and activation 4 (higher activation level), totalling nearly 64%.

Centre 2 and centre 6 have the largest proportion of patients on level 1 and level 2 (lower activation levels) totalling 64% and 70% respectively.

It is important to note that case-mix may be very different in the 10 renal centres taking part in the cohort 1 pilot study and that the group of patients who completed the survey in each renal centre may not be representative of patients overall in that centre (see discussion on limitations). It is therefore difficult to make comparisons between centres.

The correlation between treatment modality and activation level could not be investigated in this research as information on treatment modality was not included in the survey, although renal units will potentially be able investigate this detail at centre level.

Figure 2 Breakdown of PAM levels by renal centre

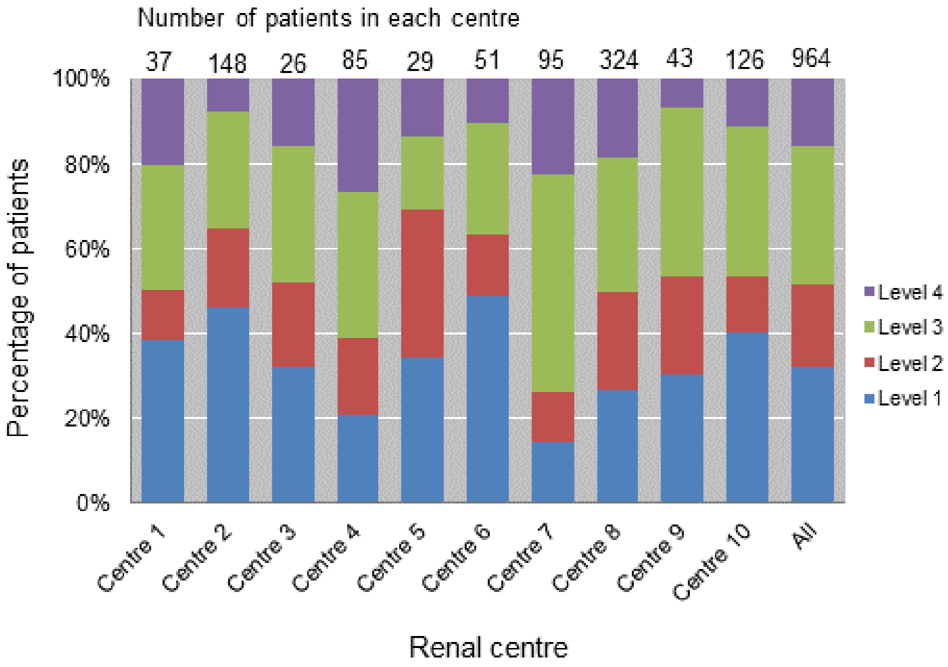


Figure 3 shows activation scores highest in age group 25-34 and activation decreasing with increasing age.

Figure 3 Median PAM score by age group

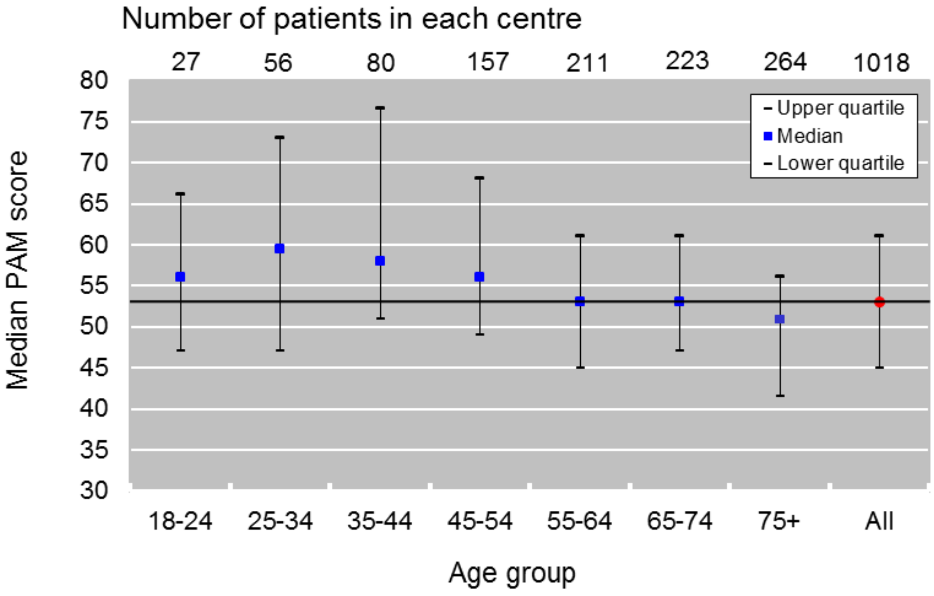
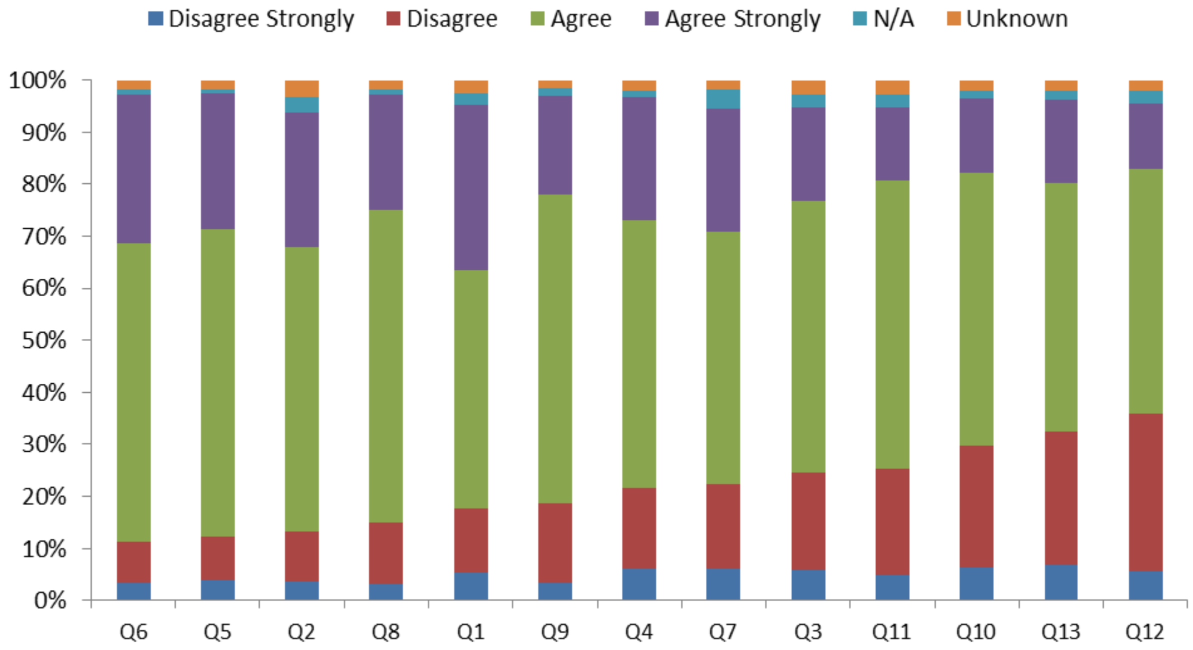


Figure 4 shows the responses to PAM questions in ascending order for patients who reported that they disagreed or strongly disagreed to the content.

About 30% of respondents found most difficulty in agreeing or strongly agreeing with questions relating to feeling confident that they can work out solutions to new health problems (question 11 and 12), maintain life style changes like healthy eating and exercise (question 10) even during times of stress (question 13) or help prevent or reduce problems associated with their health (question 3).

In contrast, 90% of respondents agreed or strongly agreed that they felt confident that they can tell a doctor or nurse concerns that they have even when medical staff does not ask (question 6) or 'take care of a problem without involving the doctor (question 5)'. At the same time they agreed or agreed strongly that taking an active role in their health was of the greatest importance (question 2).

Figure 4 PAM question scores in ascending order of patients who reported they disagreed or strongly disagreed *



*Question references

Q1	I am the person who is responsible for taking care of my health
Q2	Taking an active role in my own healthcare is the most important thing that affects my health
Q3	I am confident I can help prevent or reduce problems associated with my health
Q4	I know what each of my prescribed medications do
Q5	I know whether I need to go to the doctor or take care of a problem myself
Q6	I can tell a doctor or nurse concerns I have even when he or she does not ask
Q7	I am confident that I can carry out medical treatments at home
Q8	I understand my health problems and what causes them
Q9	I know what treatments are available for my health problems
Q10	I have been able to maintain lifestyle changes, like healthy eating or exercising
Q11	I know how to prevent problems with my health
Q12	I am confident I can work out solutions when new problems arise with my health
Q13	I am confident that I can maintain lifestyle changes, like healthy eating and exercising, even during times of stress

Results for Patient Symptoms

Results in this section are for the Patient Reported Outcome Measure (PROM). Table 4 presents patient symptoms with the prevalence determined as the proportion of patients with moderate, severe or overwhelming symptoms.

The five most prevalent symptoms were:

1. 58% of those surveyed experienced weakness and lack of energy
2. 49% of patients surveyed reported having poor mobility
3. 39% of those surveyed experienced pain
4. 38% of those surveyed reported difficulty in sleeping
5. 36% of those surveyed experienced shortness of breath

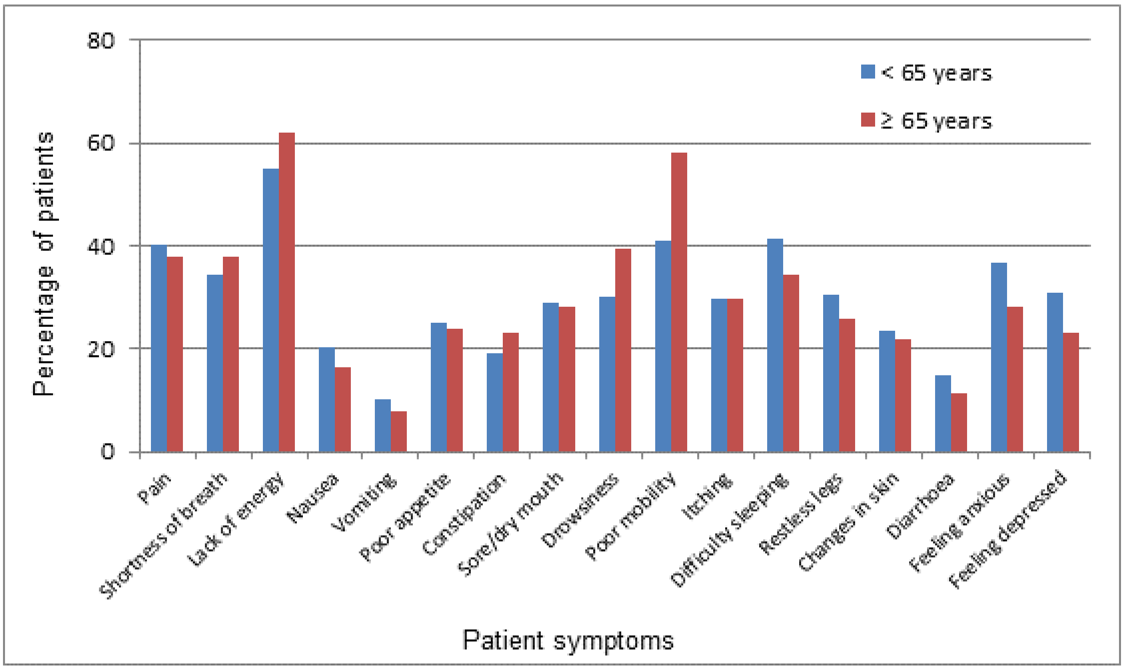
Table 4 Symptoms and how much patients were bothered by them

Symptoms	Absent/Mild		Moderate/Severe/ Overwhelming	
	Number	%	Number	%
Weakness/lack of energy	421	41.9	583	58.1
Poor mobility	508	50.7	493	49.3
Pain	608	60.9	391	39.1
Difficulty sleeping	622	61.8	384	38.2
Shortness of breath	638	63.9	361	36.1
Drowsiness	660	65.5	347	34.5
Feeling anxious/worried	677	67.3	329	32.7
Itching	704	70.4	296	29.6
Sore/dry mouth	716	71.5	285	28.5
Restless legs	714	71.7	282	28.3
Feeling depressed	725	72.8	271	27.2
Poor appetite	764	75.6	246	24.4
Changes in skin	772	77.4	226	22.6
Constipation	789	79.0	210	21.0
Nausea	816	81.5	185	18.5
Diarrhoea	865	86.7	133	13.3
Vomiting	910	90.8	92	9.2

Figure 5 shows that older patients have substantially poorer mobility, less energy and experience more drowsiness than younger patients.

Younger patients, on the other hand experience more sleeping difficulties, restless legs and feel more anxious and depressed than older patients.

Figure 5 Percentage of symptoms by age group for patients with moderate, severe and overwhelming symptoms



Results Overall Health

Table 5 presents the results for the overall health section of the survey and results agree with those in table 4 showing that nearly 50% of those surveyed suffer at least moderately with poor mobility and performing usual activities. Nearly 40% of patients report being at least moderately affected by pain and discomfort.

Table 5 Problems with general health aspects

Having problems with	None/Slightly		Moderate/severe/ overwhelming	
	N	%	N	%
Mobility	519	51.3	493	48.7
Usual activities	527	51.9	488	48.1
In pain/discomfort	614	60.8	396	39.2
Anxious/depressed	744	73.4	270	26.6
Self-care	772	76.3	240	23.7

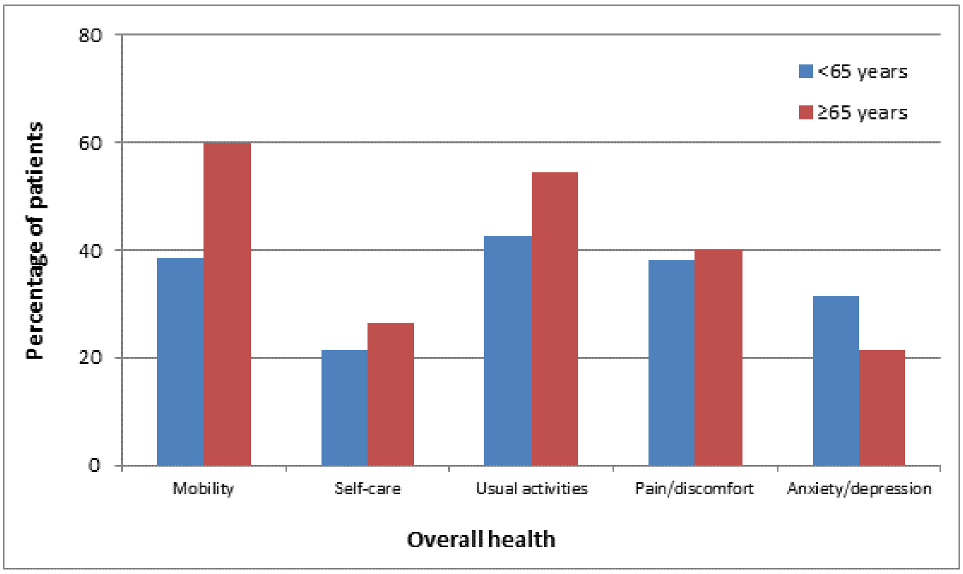
Figure 6 illustrates the prevalence of general health problems reported by patients.

Sixty percent of those surveyed in the ≥65 age group reported moderate to extreme mobility problems.

Sixty percent of those surveyed in the ≥65 age group also reported moderate to extreme problems in carrying out activities of daily living.

Prevalence of pain or discomfort was similar between younger and older patients, but patients in the <65 age group experienced more feelings of anxiety and depression than older patients.

Figure 6 Percentage of patients by health aspect and age group who reported at least moderate problems



Comparison with other research

A higher average PAM score (59.4 vs 54.5 in this research) was reported in the study by Ellins *et al.* where the PAM survey was telephonically conducted on a random sample of the UK population in adults > 45 years of age to describe the extent to which people with chronic conditions feel able to self-manage [7]. Of the surveyed UK population, 72% had a chronic health condition and 8% surveyed at PAM level 1, with 33%, 39% and 21% on levels 2-4 respectively [7]. The validation of the German PAM in primary care patients reported a mean PAM of 68.3 [8]. Validation of the Dutch PAM in patients with chronic disease and disability reported a mean activation score of 61.3, with 17.1%, 19.5%, 32.1% and 31.2% of patients on PAM level 1-4 respectively [9]. The Danish PAM validated in Danish patient with dysglycaemia also reported a higher average PAM score of 64.2 [10].

A study by Hibbard *et al*. estimated that between 25% and 40% of the population have low levels of activation (levels 1 and 2) [11]. These people are unlikely to respond to opportunities to improve their health through self-management. The level of patient activation varies considerably in the U.S. population, with less than half of the adult population at the highest level of activation, according to a new study by the Centre for Studying Health System Change (HSC) [11]. More recent applications of PAM are measuring the effectiveness of interventions and in performance measurement of health care organisations [12]. NHS Kidney Care has previously implemented PAM in some NHS trusts for a limited time period to measure the effectiveness of improving patient care programme [12].

A systematic review of symptoms in patients with end-stage renal disease reported on the prevalence of symptoms and were mostly patient reported [13]. There was variation in the definitions of symptoms between studies and in the time period for reporting symptoms and this resulted in a wide range for the prevalence of symptoms reported between studies included in the systematic review. The weighted mean for all studies for pain was reported as 47%, whereas the prevalence of pain in this research was 39.1% when defining the prevalence of pain as moderate, severe or overwhelming. Using a definition of pain as mild, moderate, severe or overwhelming, the prevalence of pain in this research increases to 59.5%. The prevalence of itching was reported as 55% in the systematic review compared to 29.6% or 55.4% using the alternative definition of prevalence. Prevalence of other symptoms in the systematic review was: 30% for restless legs syndrome vs. 28.3% (53.3% alternative definition), sleep disturbance was 44% vs. 38.2% (61.4% alternative definition), 53% for constipation vs. 21.0% (40.3% alternative definition), anxiety was 38% vs. 32.7% (56.1% alternative definition), 27% for depression vs 27.2% (49.3% alternative definition). The survey used for symptoms in this research did not capture the prevalence of abdominal pain (18%), cough (15%), cramps (46%) or anorexia (49%) that were reported in the systematic review, although the prevalence of poor appetite were reported as 24.4% (46% alternative definition) in this research and would capture some of the information reported for anorexia.

Limitations

One limitation to this research is that patients only completed the survey once, and that their answers may have been influenced by how they felt on the day of survey completion. Asking patients to participate in the survey more regularly, would help to get more insight into how their scores vary over time.

Lack of privacy when completing the survey, either because patients were assisted with completion or because they did not complete it at home, may have affected patient's answers.

Patients completing the survey are self-selective, and we do not know whether they are representative of patients on RRT or CKD patients in England. If there is bias in the results, it will possibly be more towards patients who are interested in their health care as opposed to those who rely more on clinical staff to make the decisions. Compared to the age distribution of all RRT patients in England, a larger proportion of patients aged 75+ years completed the survey, whereas the smaller proportion of patients <65 completed the survey.

The UKRR is currently unable to report on the association between PAM level and treatment modality as modality data were not included in the survey.

Conclusions and next steps

The data collection from this survey provides novel information on the population of patients on RRT in England and for the first time patient activation, symptoms and overall health can be evaluated and benchmarks established.

Many people living with CKD completed the survey, more than half doing it themselves, without needing help from others. This is a promising starting point for using the survey on a wider scale.

One in three patients reported feeling overwhelmed by their illness, and preferred that their doctor make the decisions about their health.
At the same time, a similar proportion said that they had the knowledge, skills and confidence to be actively working with their health care team to manage their condition.

Many respondents (30%) felt they lacked the confidence to work out solutions when new health problems would arise, and did not feel able to maintain lifestyle changes.

From the above we would recommend that there is a need to explore and test interventions to build knowledge, skills and confidence (activation) for people with CKD and see if these are associated with improved patient outcomes.

At the same time more than half of all respondents reported to be at least moderately bothered by lack of energy. Poor mobility, pain and difficulty sleeping were also very common.

It is clear from this data that people with CKD carry a considerable symptom burden that at times may be invisible and highlights the importance of understanding and managing the symptoms in CKD patients.

This data is disseminated to patients via Patient View (PV) and clinical teams receive results as an excel spread sheet. Phase 2 of the programme will be about supporting patients to gain knowledge, skills and confidence to participate as equals in their care. At the same time it is looking at a cultural shift by facilitating teams to reflect on their conversations and behaviours with a view to new ways of working to support patients in gaining these skills. It is planned to be used to empower patients, influence the style and content of clinical consultations, and potentially foster further discussions about departmental approaches to the management of patients with long term conditions. The knowledge and experience gained from this transformative approach can be shared widely to encourage and sustain cultural change which can be applied to the delivery of services and involvement of patients with other long term conditions.

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