Transforming Participation in Chronic Kidney Disease

Programme Report

January 2019

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Programme review

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Authors' acknowledgment

The authors thank everybody who generously gave their time to take part in and support this programme. In particular we would like to acknowledge the patient members of the programme board and workstreams, especially those who co-chaired, contributing lived experience as well as an essential voice that challenged and enhanced this programme.

We would also like to say a big thank you to the participating unit teams who committed to and supported the programme sharing their challenges and successes in implementing change. It has been an extremely rewarding experience but is a journey that has only just begun.

Foreword

Richard Fluck, FRCP, MA (Cantab), MBBS
Consultant Renal Physician, Royal Derby Hospital

It is a great pleasure to provide this foreword, in conjunction with my co-chair, Jonathon Hope. The lessons from this work are of relevance to people with kidney disease, to people with other long-term conditions and the wider NHS, to the public and to the professionals who deliver the care and services, whether as a multi-professional clinician or commissioner.

This project addresses a central question that health care in the 21st century needs to answer. How do we improve people's knowledge, skills and confidence in managing their own health and illness? Without solutions to this question, the complexity of health care is likely to widen the gap between the best and worst outcomes that we see across the nation.

This report does not give the complete solution, but it is a step on that journey. It has examined the feasibility of measuring an individual's knowledge, skills and confidence using a recognised system that is transferable and comparable. It has identified the characteristics of a team that allows such tools to be introduced into routine clinical practice. It has posed the challenge of how to change the engagement of individuals and of teams in delivering better health. Its biggest success though is, perhaps, in showing how service users and service deliverers can work together for a better solution.

The programme delivers a series of recommendations for providers of care, patients, the professionals at the coal face, the commissioners who provide the wherewithal, and the core data needed to improve the system of care. Going forward, I am pleased to see that NHS England recognises the importance of this work and the skills of the team by supporting a second phase of this project to begin the task of improvement.

Richard Fluck

Jonathon Hope MBE
MBE for services to renal patients

The current approach to renal failure is highly medicalised and nearly 50% of us (I speak here as someone living with CKD) end up on kidney machines. This can result in many of us feeling passive, uninvolved in our care, isolated and disempowered, with outcomes and a quality of life that are amongst the worst of any of those with a long-term condition.

The ‘Holy Grail’ for most people with a chronic disease is to reclaim what is often lost in the face of a long-term condition: *hope; empowerment; independence; control and well-being*; but for most of us, reclaiming what is lost in our daily lives - often without or outside of the support of the healthcare system - is a mammoth struggle with no guarantee of success.

What excited me most about co-chairing this programme was its potential to map out and potentially deliver some of the steps needed to systematically empower or ‘activate’ patients across an entire pathway of care. In this report we share some of our learning around how this shift might be designed and delivered and the systems, practices and skills needed to bring about such a radical and widespread shift in the balance of power from healthcare professionals to those of us with a long term condition. Our own conclusion in this programme was that from the start, we would try hard to “*be the change we wanted to see”* in the NHS.

We worked hard to partner with patients, carers and patient leaders in the process of design itself. In every step of this programme, we tried to walk hand in hand with patients, carers and patient leaders. What we learned about how we achieved that will soon be published in a separate report on *co-production* to be found on the Think Kidneys website.

Trying to genuinely share power with patients in this programme challenged us as leaders, yet despite this, it delivered many benefits to this programme and its outcomes; much of our approach was innovative and empowered patients and patient leaders in an unprecedented way.

This report also holds out a vision of an NHS of the future whose focus and responsibility lies in empowering both staff and patients. It is a vision that has the potential to benefit all – patients, clinicians, staff, providers, commissioners. It is a vision based on equality, on sharing responsibility and power and on an extraordinarily exciting concept: that when given the right support, tailored to each individual living with a chronic health condition, we can be empowered to reclaim as much control, health and well-being in our lives as we are able – despite the very significant burden that living with such a condition may entail.

Contents

Executive summary, key messages and recommendations

The success of treatments has historically been assessed using measures considered important by the professionals delivering care. However, these measures do not capture many other outcomes that are of great importance to patients, such as readiness to engage in their care, symptom burden or experiences of care. Many of the instruments measuring the patient's perspective have been available for decades, yet their incorporation into routine clinical practice has been slow.

In 2016, NHS England provided a measure of patient knowledge, skills and confidence to make effective decisions and take action to maintain or improve one's health (the Patient Activation Measure® or PAM® (1)) to several organisations. A growing body of research has shown low activation is associated with a higher symptom burden, reduced quality of life and poorer outcomes and that increasing activation can reduce health inequalities, deliver improved outcomes, better quality care and lower costs. Furthermore, appropriately designed interventions can increase patient activation, often bringing about associated improvements in health and wellbeing (2). Currently the interventions that improve activation are often viewed as outside of the clinical domain as they primarily are behavioural in nature rather than bio-medical.

Kidney patients are intensive and persistent users of healthcare services and have a high level of morbidity and mortality. This makes them an ideal group in which to study the feasibility of collecting these measures and evaluate the potential benefits. Transferable learning from this study provides important insights into the way healthcare and outcomes could be improved for other groups of patients.

Collecting patient measures from people with long-term conditions has great potential value to health care professionals and patients, providing support for shared decision making about choice of treatment modalities and supporting increased participation in self-management.

The Transforming Participation in Chronic Kidney Disease Programme (TP-CKD), a collaboration between the Renal Association and NHS England, implemented Patient Activation Measures (PAM) and Patient Reported Outcome Measures (PROM) across 14 renal units in England. The programme commenced in January 2015 and completed December 2017.

The main aim of the programme was to test the feasibility of routinely collecting patient reported measures including assessment of patients' knowledge, skills and confidence in self-managing their health (PAM), their symptom burden (POS-S renal (3)) and their quality of life (QoL) (EQ5D-5L (4)). These instruments were embedded into a survey tool known as

Your Health Survey. Renal units were taken through the peer assisted programme by a person centred care facilitator (PCCF), focussing on nine key stages of implementation aligned to the NHS Change Model.

This report describes the nine aspects of the programme in detail, aligning these with the challenges faced and successes achieved by the 14 units, in order to share best practice and opportunities for learning.

The secondary aim of the programme was to explore the potential associations between patient activation, symptom burden, QoL and biomedical markers. This report also describes the findings of this analysis.

A subsidiary aim of the programme was to collect an additional measurement known as the Clinical Support for Patient Activation (CS-PAM). This tool enabled the capture of information on the clinical teams' support of patients to self-manage and was collected initially in ten units as benchmarking data at the beginning of the programme. The purpose of collecting the CS-PAM was to attempt to gauge a unit's readiness to begin implementation of *Your Health Survey* and gain an understanding of potential barriers that might impede this, in order to address them. Any potential correlation between CS-PAM and unit culture is discussed later in the document. The overall CS-PAM benchmarking data is a separate report which can be accessed here.

Key findings

The programme recognised that it is challenging to implement and collect patient reported measures routinely. However, it demonstrated that with a structured approach and support it is feasible to routinely collect patient reported measures in patients with moderate to severe chronic kidney disease (CKD) and those on renal replacement therapy (RRT) in England. This support was structured around the NHS Change Model and a Peer Assist approach.

What does it mean for implementers?

The main aim of the study was to assess the feasibility of gathering data on kidney patients' knowledge, skill and confidence to self-manage, QoL and symptom burden, as part of their usual care in the form of the *Your Health Survey*. The study shows:

- The UK Renal Registry (UKRR) as part of the Renal Association has developed the infrastructure to receive and process patient reported data on paper and to support the return of data from *Your Health Survey* to patients and to providers

- Providers can collect *Your Health Survey* from people on RRT (dialysis and transplantation) and with CKD in England. Routine collection was established in the haemodialysis and transplant population although routine collection in CKD patients was less straightforward. One of the main reasons for this was their irregular clinic attendance

- All units developed a way of collecting CS-PAM data from the staff they identified as relevant. Measures were completed predominantly by nursing staff and allied healthcare professionals, with fewer measures completed by medical staff

- The pilot identified common characteristics of the renal units which facilitated successful collection of these measures. These include senior leadership, patient involvement and team engagement

- Factors such as a depleted work force, staff time and competing priorities hindered successful implementation of these measures within renal units

- Including patients with health professionals in the leadership, co-production, and co-design of the programme at national and local level enhanced the delivery of the programme and provides the foundation for future service development

- Additional resource may be required if a co-productive approach is to be sustainable for future projects

- A peer assist change model provides a positive approach to share learning and experiences to help overcome challenges

- Up-skilling of the clinical workforce is required to support ongoing collection of these measures and the use of them as a clinical tool within practice

- Patient reported measures need to be embedded into clinical IT systems to regularise and sustain their use. This makes them easier to access and use in consultation. Having fit for purpose IT systems is also important for recording service use providing data for monitoring, evaluation and commissioning purposes.

What does it mean for patients?

- Around half of all patients reported feeling overwhelmed by their illness and felt that their clinical team made the important decisions about their health with little or no input from themselves

- Around half of all patients reported that they had the knowledge, skills and confidence to be part of their health care team
- People using in-centre haemodialysis demonstrated lower patient activation scores than those with either a transplant, using peritoneal dialysis or with reduced kidney function (CKD)
- Lower activation levels were associated with lower health-related QoL and a higher symptom burden
- No correlation was found between patient activation and patients' biomedical markers such as haemoglobin, calcium and phosphate
- The five symptoms most often reported varied slightly by treatment although weakness and lack of energy was the most reported common symptom
- Symptom burden was highest in haemodialysis patients and lowest in transplant patients
- Around half of all patients experienced at least moderate problems with performing normal daily activities, with a higher percentage of in-centre haemodialysis patients reporting this as a problem
- Elderly patients (>65 years old) with lower deprivation scores and lower activation levels generally reported a higher symptom burden and lower QoL
- Younger patients (<65 years old) reported more symptoms of anxiety and depression than older patients.

Recommendations

Commissioning

Commissioning tools and levers should be developed to support the use of patient activation measures and the use of the *Your Health Survey* tool. This could provide data for further analysis of the relationships between interventions, patient activation, and quality of life outcomes. Including PROMs could extend the scope of measurement for comparing unit performance, and encourage a renewed focus on these wider aspects of care. This could include inclusion in service specifications, dashboards and the use of incentive schemes.

Providers

- Those implementing patient reported measures should consider giving a specific person(s) responsibility to co-ordinate collection, whilst ensuring the whole team understands and engages with the work
- Electronic systems should be capable of utilising such information at the point of care
- Providers should ensure data is returned to the UKRR for the purpose of audit
- Education and support should be provided to professionals to embed measurement and aid the delivery of necessary interventions
- Providers should consider clinical champions to lead adoption and engagement.

Professionals

- Professionals should undertake training to better understand the support needs of patients with low activation and high symptom burden
- Professionals should undertake training in core behaviour change models to support activation
- CS-PAM should be utilised as a reflective tool to support up-skilling
- Professionals should use patient reported measures alongside medical information and data in supporting the health of patients.

Patients

- Patients need to have access to *Your Health Survey* and their electronic results via PatientView[1] to help manage their condition alongside clinical teams
- Patients need to be able to access support and education to take a more active role in their health and care.

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[1] PatientView is an online platform that allows renal patients to view their test results, clinic letters and information about their kidney care and treatment. The platform is available to patients if their hospital or renal unit has signed up to it

UK Renal Registry

- The UKRR should continue to support the collection and analysis of these data as part of their core business
- The UKRR should develop a toolkit to facilitate implementation across the renal community building on the approaches used in this programme such as Peer Assist.

Introduction

Supporting patients to self-manage as effectively as possible is a fundamental component of person-centred care, a key component of NHS England's Five Year Forward View (5), a key priority for the Health Foundation (6), and a central feature of manifestos and policy guidance from leading patient groups (7).

> *"Nothing less than a transformation is required: in the relationship between patients and professionals, and to embed effective tools and techniques to facilitate patient participation into mainstream models of care (6)"*

Current ways of working, in the main, do not support such an approach. If a patient's involvement in their own care is to be improved resulting in improved outcomes, ways must be found to support them and clinical teams to work in partnership towards this change. Healthcare professionals need to be able to assess the willingness and readiness of patients to take greater control of their health and well-being and to understand the capacity of health care teams to support patients in this endeavour. This will allow support and training to be appropriately tailored and targeted to both professionals and patients.

CKD is a common and harmful condition affecting one in ten adults within the UK and accounts for £1.45 billion of annual NHS expenditure (8). Public Health England (2017) estimates CKD as the ninth leading cause of morbidity, with patients at increased risk of multi-morbidity (9) (10).

Diabetes is the most common identifiable cause but a wide range of inherited and acquired conditions can cause CKD. Some people with CKD will progress to end-stage kidney disease and many of these will benefit from RRT. Many more, though not progressing, have shortened life expectancy due mainly to an increased risk of cardiovascular disease and acute kidney injury.

Advanced CKD has a profound impact on an individual's general health and wellbeing, with a high symptom burden dominated by chronic tiredness, pain and depression, reduced physical activity and function, poor social inclusion, dependence, and inability to perform activities of daily living (11). Treatments such as dialysis and transplantation, although life sustaining, are at times onerous and never curative. As a result, both lifespan and QoL are markedly reduced. Indeed, the prognosis of patients on dialysis is poorer than that for many common cancers (12).

The success of treatments has historically been assessed using measures considered important by the professionals delivering care. However, these measures do not capture many other outcomes that are of great importance to patients, such as readiness to engage in their care, symptom burden or experiences of care. Many of the instruments measuring the patient's perspective have been available for decades, yet their incorporation into routine clinical practice has been slow. Lord Darzi's report *High Quality Care for All – NHS Next Stage Review* (13) and the subsequent requirement to report PROMs around four surgical procedures provided a real opportunity to make health outcome reporting in the UK more relevant to the patient.

In 2016, NHS England provided a measure of patient knowledge, skills and confidence in self-managing their health (the Patient Activation Measure) to several organisations. The UKRR has, for many years, routinely collected data on biomedical and haematological parameters, blood pressure control, dialysis adequacy and survival. It was believed that extending this to include parameters such as patient activation and PROMs would be a valuable addition. The benefits of this include the capacity to feedback such data to renal units in a timely fashion to allow its use to inform clinical consultations and thus to enhance person-centred care. Another major benefit is that elements of this data could extend the scope of items used in comparing unit performance.

Aims and objectives

The aim of the TP-CKD programme

The TP-CKD programme was a collaboration between NHS England and the Renal Association with a primary aim to determine the feasibility of renal units routinely collecting patient reported measures such as symptom burden, QoL and the ability to self-manage from kidney patients and return the data to the UKRR.

Further aims of the programme included:

- To explore the knowledge, skills and confidence of people with kidney disease to self-manage their health and the association that symptom burden might have on this and QoL outcomes
- To examine the capacity of health care professionals to support such involvement, and methods which might enhance both of these
- To develop an intervention toolkit and test the efficacy of targeted interventions to improve activation.

Central to the aims of the TP-CKD programme was finding ways to empower patients and health care professionals to create new ways of working which support patients to take greater control of their health and wellbeing, greater involvement as equals in the design and delivery of new services and to achieve the personal and clinical goals that are important to them.

The objectives of the TP-CKD programme

1. Assess the feasibility of gathering data on kidney patients' knowledge, skill and confidence to self-manage, QoL and symptom burden, as part of their usual care

2. Explore whether kidney patients with higher levels of knowledge, skill and confidence in self-management have a better QoL and a lower symptom burden

3. Identify interventions that may improve a patient's level of knowledge, skills and confidence in self-managing their health - known as their 'activation'.

The report

This report describes progress in addressing objectives 1 and 2. It consists of two sections:

Section 1: Reviews the feasibility of routinely collecting patient activation measures (PAMs) and patient reported outcome measures (PROMs) in kidney patients through the UKRR and reports response rates, successes and barriers to routinely collecting the data for these measures.

Section 2: Reports on the potential associations between PAM, symptom burden and QoL.

Status of objective 3: Additional funding has been awarded by NHS England to test the role and impact of interventions in improving knowledge, skills and confidence of kidney patients and the impact this might have on other outcomes such as symptoms, QoL and health resource. The study to test objective 3 will focus on four units who either successfully participated in the TP-CKD programme or the NHS England PAM Commissioning for Quality and Innovation (CQuIN) and build on their learning.

TP-CKD programme design and delivery

The TP-CKD programme was developed between January and July 2015, commencing with a national programme co-design event involving patients, carers, clinicians, NHS England representatives and commissioners, followed by the establishment of a programme board and workstreams. The role of the measurement workstream was to agree a set of patient-reported measures suitable for routine collection. The role of the intervention workstream was to develop and agree targeted interventions for patients and clinical teams to support patients' active participation in their own health care, published in the form of an intervention toolkit. This workstream informs and supports the work that is currently being developed around objective 3.

The Change Model

The NHS Change Model[2] (Figure 1) was used to frame the TP-CKD programme; the eight elements were used to design the improvement structure of the programme (Table 1) which was then briefed to units via detailed guidance on what each stage encompassed. A PCCF was recruited to support participating units with their improvement plans.

Table 1: Unit criteria

NHS Change model	TP-CKD criteria
Shared purpose/vision	Programme vision outlined in aims and objectives
Leadership for change	Working groups Champions and leaders Senior buy-in
Spread of innovation	Peer assist Communication
Improvement methodology	Quality Improvement (QI) cycles Peer assist 30-60-90 day plans
Rigorous delivery	PCCF Programme delivery board UKRR infrastructure 30-60-90 day plans
Transparent measurement	Data collection
System drivers	NHS England – collection of PAM and PROM Five year forward view Person-centred care drivers
Engagement to mobilise	Engagement of the whole team Co-production

Figure 1: The NHS change model

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[2] For further reading, visit **www.england.nhs.uk/sustainableimprovement/change-model/**

The survey tool

The *Your Health Survey* tool developed by the measurement workstream consisted of:

- Five questions on QoL (EQ-5D-5L (4))
- 17 questions on symptoms (POS-S renal (3)), and
- 13 questions on the ability of the patient to manage their health (patient activation measure or PAM (1))

The programme recognised that targeting interventions solely at patients was unlikely to achieve the necessary culture change, since this would also require health professionals to be sufficiently ‘activated’ to engage with patients in a way that improves activation. The skills, knowledge and confidence cube (Figure 2), designed by the programme team, illustrates an ‘activation space’ defined by both the patient’s and health professional’s levels of activation, in which the level of health professional activation may play a crucial role in motivating or demotivating patients with respect to engagement in self-management. Likelihood of achieving full involvement of patients in their own care is dependent on both their own level of activation and the level of activation of the people looking after them (14).

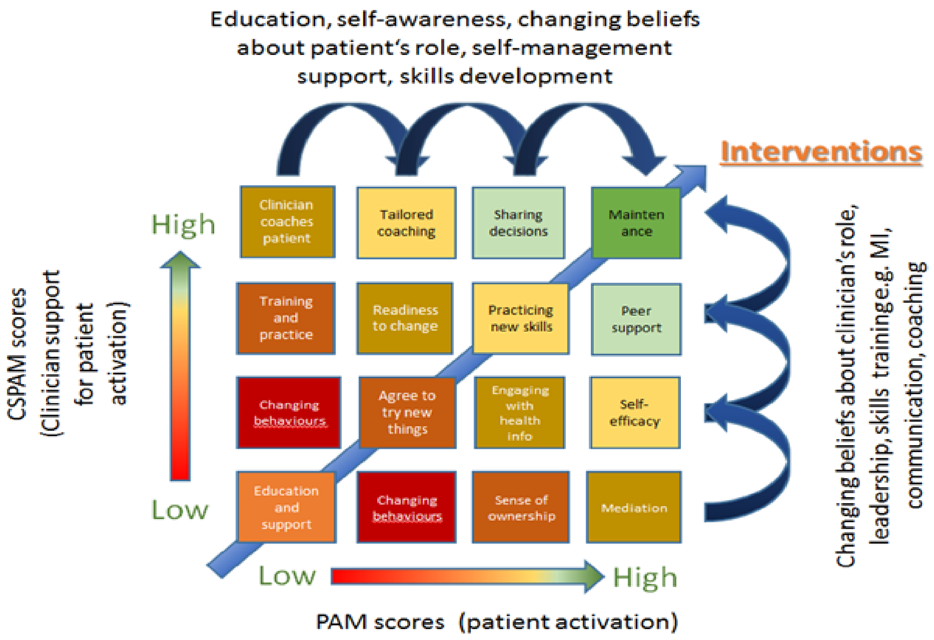

Figure 2: Knowledge, skills and confidence cube

With this in mind the Clinical Support for Patient Activation (CS-PAM) was recommended as an additional measure. NHS England also suggests that the CS-PAM can be used as a reflective tool for clinicians. This tool enabled the capture of information on the clinical teams’ support of patients to self-manage and was collected initially in ten units as benchmarking data at the beginning of the programme. The purpose of collecting the CS-PAM was to attempt to gauge a unit's 'culture' and readiness to begin implementation of *Your Health Survey* and to gain an understanding of potential barriers that might impede this.

Potential links between CS-PAM responses and unit culture are discussed later in the document. The initial CS-PAM benchmarking data is a separate report which can be accessed here.

IT Infrastructure

IT infrastructure within the UKRR was developed to support the processing of patient reported measures. This included:

- Installing scanning software to computerise *Your Health Survey* and Patient Reported Experience Measure (PREM) responses[3]
- Linkage to the UKRR database to support the validation of patient demographic information and electronic storage of results on the central database
- Installing new online pages on PatientView in order to display *Your Health Survey* results
- Linkage to enable results to automatically be fed through to PatientView so that patients and clinicians have access to *Your Health Survey* results.

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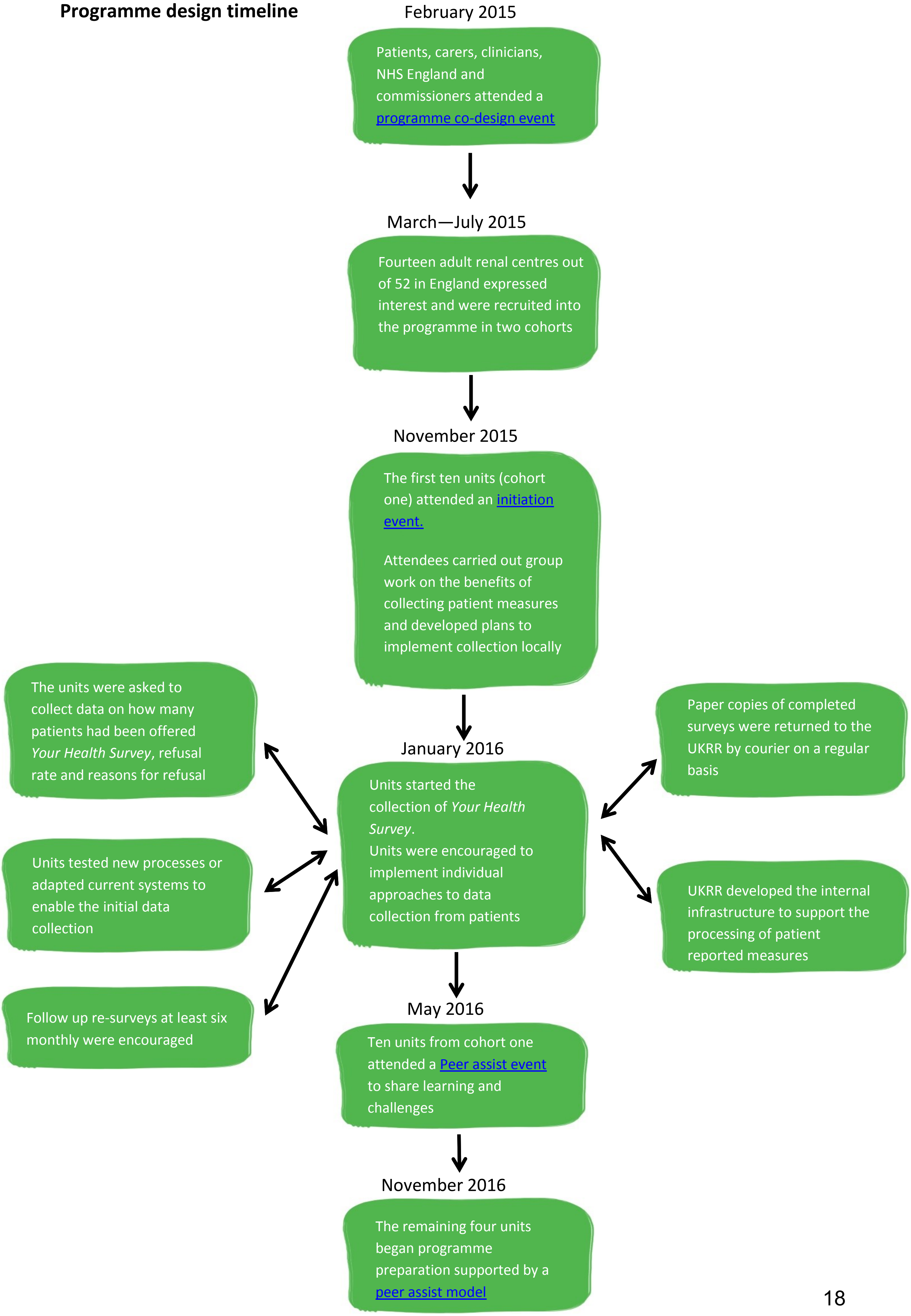
[3] The measurement workstream co-designed a kidney PREM tool as part of the TP-CKD programme. This tool has been adopted nationally and is reported annually by the UKRR. This report does not include details of the national PREM results, but to find out more visit http://www.renalreg.org/projects/prem. You can read the 2017 national PREM report here

Programme design timeline



February 2015

Patients, carers, clinicians, NHS England and commissioners attended a programme co-design event

March—July 2015

Fourteen adult renal centres out of 52 in England expressed interest and were recruited into the programme in two cohorts

November 2015

The first ten units (cohort one) attended an initiation event.

Attendees carried out group work on the benefits of collecting patient measures and developed plans to implement collection locally

January 2016

Units started the collection of *Your Health Survey*.
Units were encouraged to implement individual approaches to data collection from patients

The units were asked to collect data on how many patients had been offered *Your Health Survey*, refusal rate and reasons for refusal

Units tested new processes or adapted current systems to enable the initial data collection

Follow up re-surveys at least six monthly were encouraged

Paper copies of completed surveys were returned to the UKRR by courier on a regular basis

UKRR developed the internal infrastructure to support the processing of patient reported measures

May 2016

Ten units from cohort one attended a Peer assist event to share learning and challenges

November 2016

The remaining four units began programme preparation supported by a peer assist model

Programme guidance

This guidance was provided to staff and patients at the renal units during the preparation phase to support the successful implementation of *Your Health Survey*. It was made available as a written document, both electronically and in hard copy format and its use and value was reinforced and discussed at subsequent events and meetings. The nine guidance points outlined below were developed and expanded during the programme and used by the PCCF and programme board as a basis from which to assess the success of the individual units in implementing processes to collect *Your Health Survey* data.

Peer assist

Participating teams were encouraged to:

- Attend and participate in the peer assist events during the life of the programme
- Share lessons learned with other participating units to support implementation plans and potential challenges
- Attend monthly calls with other participating units to share the successes and challenges of their implementation plans
- Write blogs and case studies for the website to support sharing and learning

Peer assist

A peer assist model was agreed by the TP-CKD programme to provide support to the participating units and as a framework for change. Peer assist is also known as 'learning before doing' and describes a team asking for help through the following process:

- Inviting people with previous experience to share their experiences, insights and knowledge with the team
- Check whether others have faced similar problems/issues and solved them
- Hold problem solving/sharing sessions involving teams working together and presenting learning and recommendations back to the team

30-60-90-day plans

- Units were tasked to develop 30-60-90-day implementation plans during the peer assist event and return with them to their units to consolidate
- The units were asked to consider within these plans how best to engage their wider team of staff and patients
- Each unit was asked to make available their plans so other participating units could learn from them and the PCCF could help support the delivery in each unit

Working groups

- It was suggested that each unit should form a working group based on the team attending the peer assist event. The groups would meet regularly and agree actions that would be fed back through the governance structure of the individual units
- The groups were encouraged to have equal representation of staff and patients, a good skill base to aid implementation, and to be led by a senior clinician and a patient champion

Champions and leaders

- Units were asked to nominate local champions to provide the support and drive to implement the required change
- Champions might be a patient and a member of the clinical team, not necessarily a senior member

Senior ‘buy in’

- Pro-active support and endorsement at senior leadership level, such as clinical director and/or lead nurse, was required to align the programme with other competing priorities within the unit and ensure appropriate levels of support

Quality improvement

- Units were encouraged to try out small scale, incremental change in a chosen part of the pathway rather than scale up immediately
- The emphasis was not on numbers and spread of the data collection but about using the programme as a learning journey to test ways of working that could embed collection of these measures as a routine, sustainable part of practice
- It was recommended that an ‘After Action Review’ (AAR) was carried out to enable the sharing of the learning both internally and with the wider programme
- Units were also encouraged to involve their local Trust Quality Improvement leads as a way of gaining support and guidance for the programme

Co-production

- Co-productive working between unit staff and patients in the planning and delivery of these developments was an important principle that was encouraged
- There was an aspiration of equal representation of unit staff and patients on local working groups and on unit teams attending peer assist events

- Units were encouraged to develop ways of working that best harnessed patient skills and experience and did not necessarily need to be face to face meetings

Engagement of the whole team

- It was recognised that to embed sustainable change, wide engagement of the whole team was required, focussing on enhancing person-centred care, not just data collection
- The PCCF based at the UKRR acted as a resource to support wider engagement and meet with multidisciplinary teams and Kidney Patient Associations as early in the programme as appropriate. This was offered as regular face to face meetings, conference calls and hosting workshops to discuss data and how it could be used in practice

Communication

- The PCCF set up monthly calls that the units were encouraged to attend (patients and staff) to share learning and discuss challenges and successes of implementation
- Units were encouraged to share and discuss innovations with other units, to present them at the Peer Assist events and to share learning via monthly calls, blogs and case studies
- Information about the programme and resources were shared through the Think Kidneys website
- Units were encouraged to utilise the PCCF who offered support through visits, emails, data summaries and workshops to discuss ways to use the measurement data for patient benefit
- Units were encouraged to work with their Trust communications team, and to make use of their intranet and bulletins to share the innovation that was being implemented
- It was suggested that local media and clinical commissioning groups (CCGs) may be interested in the person-centred care perspective of the innovation.

Programme Leadership

Programme leadership was based on the principles of co-production which underpinned the programme with patients involved and influencing from the inception. Based on these principles the delivery of the programme was supported by a board comprising a range of stakeholders including patients, carers, clinicians, NHS England representation, commissioners and academics. A patient and professional were recruited as co-chairs on the board and on each workstream, with an aspiration of 50:50 patient/professional membership and this was in the main achieved. Patient and public input and influence was represented at every level of the programme from creating the programme plan to end evaluation, and from central down to local design.

> *"Co-production is not just a word, it's not just a concept, it is a meeting of minds coming together to find a shared solution. In practice, it involves people who use services being consulted, included and working together as equals from the start to the end of any project that affects them."*
> *(21)*

Programme delivery

Fourteen of the 52 renal units in England self-selected to participate in the programme and were allocated to two cohorts. Cohort one comprised ten units who were classified as early adopters of person centred care, with the remaining four allocated to cohort two. It was envisaged the latter would commence implementation at a later stage based on the learning from cohort one. All expressions of interest to participate were signed-off by the clinical directors of the 14 units who agreed to commit to the programme deliverables.

Units from cohort one were invited to an initiation event in November 2015 with the implementation of patient measures beginning in January 2016. Units from cohort two were invited to a peer assist event in November 2016 and commenced measurement in January 2017. The aim of this approach was to build on the Peer Assist model to cascade and share learning from cohort one to enable cohort two to successfully implement patient reported measures.

Under the banner of *Your Health Survey*, the programme introduced the use of the PAM survey across several populations of people with CKD, including patients with moderate to severe CKD attending renal outpatient clinics, those on dialysis at home and in units, and those with renal transplants. Each unit also undertook collection of patient reported outcome measures - symptom burden using the POS-S renal instrument and QoL using

EQ5D-5L. In addition, units collected data on clinician support for patient activation, using the Clinical Support for Patient Activation Measure (CS-PAM).

Section 1

This section describes a review of the feasibility of routinely collecting PAM and PROMs in kidney patients from 14 renal units through the UKRR. The surveys were presented as a tool known as *Your Health Survey***.**

1.1 How successful were units in collecting data?

Successful implementation of *Your Health Survey* varied across units. All 14 units managed to collect survey data at least once from a group of patients, however only some succeeded in resurveying patients due mainly to difficulties in embedding the measure and sustaining processes to enable re-survey. In addition, incorporating discussion of patient-level survey results into care processes or clinic appointments proved challenging.

Of the 14 participating units two units dropped out after an initial data collection, five encountered challenges in the routine collection, especially pertaining to re-surveying, and seven developed robust solutions to collect and submit data. Together these seven submitted 2,697 of the total 3,325 surveys, with six units managing to re-survey. A total of 842 re-surveys were collected (Table 2).

Table 2: Participating units and number of returns

	First survey		**Re-survey**	
Unit	**Number**	**Percent (%) of 3,325**	**Number**	**Percent (%) of 842**
Unit 01	418	12.57%	134	15.91%
Unit 02	402	12.09%	133	15.8%
Unit 03	740	22.26%	286	33.97%
Unit 04	603	18.14%	125	14.85%
Unit 05	197	5.92%	21	2.49%
Unit 06	164	4.93%	42	4.99%
Unit 07	173	5.20%	7	0.83%
Unit 08	109	3.28%	0	0.00%
Unit 09	111	3.34%	34	4.04%
Unit 10	104	3.13%	28	3.32%
Unit 11	53	1.59%	27	3.21%
Unit 12	128	3.85%	0	0.00%
Unit 13	43	1.29%	2	0.24%
Unit 14	52	1.56%	0	0.00%
Unit unknown	28	0.84%	3	0.36
	3,325	**100.00%**	**842**	**100%**

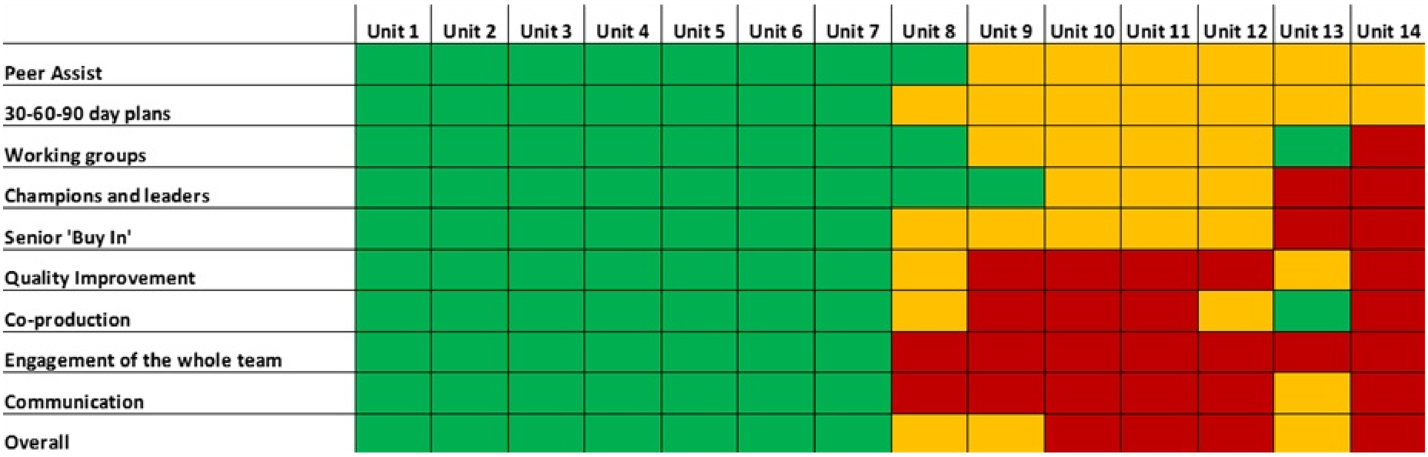
Assessment of units using a Red Amber Green (RAG) rating

RAG rating of each participating unit, according to predefined characteristics incumbent in the nine criteria outlined in Table 1, was carried out by the PCCF at regular intervals throughout the programme and shared with the core team and programme board. The main purpose of this was to help prioritise the support given by the PCCF to units at differing stages of readiness for programme implementation and also to build an overall view about what was and was not working regarding the collection of the patient reported measures. Ratings were subjective and arrived at with reference to examples of good practice and solution-finding in response to the challenges faced and were not formally shared with the units. The final RAG rating was used to help define the unit characteristics associated with successful routine collection of patient measures and was validated by the TP-CKD board.

Results of the RAG rating in 14 units

Table 3 shows the final RAG rating of the 14 participating units, together with an overall assessment of the unit to indicate a preponderance of characteristics likely to facilitate successful engagement with the programme. Those units rated green were seen to have adopted the majority of the pre-defined characteristics, whilst those rated red did not adopt the majority. There was some correlation between these overall RAG ratings and success in achieving routine collection of patient measures (vide infra).

Table 3: RAG assessment of participating units



	Unit 1	Unit 2	Unit 3	Unit 4	Unit 5	Unit 6	Unit 7	Unit 8	Unit 9	Unit 10	Unit 11	Unit 12	Unit 13	Unit 14
Peer Assist	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟨	🟨	🟨	🟨	🟨	🟨
30-60-90 day plans	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟨	🟨	🟨	🟨	🟨	🟨	🟨
Working groups	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟨	🟨	🟨	🟨	🟩	🟥
Champions and leaders	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟨	🟨	🟨	🟥	🟥
Senior 'Buy In'	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟨	🟨	🟨	🟨	🟨	🟥	🟥
Quality Improvement	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟨	🟥	🟥	🟥	🟥	🟨	🟥
Co-production	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟨	🟥	🟥	🟥	🟨	🟩	🟥
Engagement of the whole team	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟥	🟥	🟥	🟥	🟥	🟥	🟥
Communication	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟥	🟥	🟥	🟥	🟥	🟨	🟥
Overall	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟨	🟨	🟥	🟥	🟥	🟨	🟥

1.2 Data collection: Successes and challenges

Table 4 provides examples of successes and challenges to routine collection of *Your Health Survey* in units and examples of the characteristics likely to influence engagement. Links are provided to case studies and learning to illustrate what worked and what did not work within units. Units have been anonymised within the table.

Table 4: Examples of green and red RAG ratings from participating units

	Successes and positive characteristics	Challenges and less beneficial characteristics
Peer assist **Green: 8** **Amber: 6** **Red: 0**	**Willingness to share successes and innovations but also the challenges** Actively participated in **peer assist events** through presentations and discussions After the initial peer assist event both staff and patient champions from these units planned the content and **helped facilitate subsequent events** Patients and staff **shared** blogs **and** case studies **for the website** and participated in the **monthly calls** sharing their local experiences	The units less successful at peer assist **appeared to think they had nothing important to share** **Mistakes during testing were classified as a failure** and as a result teams lost energy and direction The energy that was created during peer assist events **did not translate to motivation and innovation once back in unit**
30-60-90 day plans **Green: 7**	**Proactive planning** with a structured approach to address any potential challenges Used the time frames set out at the beginning to achieve initial aims and then **began to look beyond the 90 days to**	Although all units completed the 30-60-90 day plans the less successful centres **did not identify the process, the people, the change or the results that they wanted**

Amber: 7 **Red: 0**	**next steps**	• The plan then **became a task** that did not translate to the programme vision or shared purpose
Working groups **Green: 9** **Amber: 4** **Red: 1**	• A working group was convened soon after the initial event **building on the relationships and momentum gained from the peer assist event** • **30-60-90 day plans set the initial agenda** for the group providing a structure and requirement for ongoing meetings • A group of people with a range of skills from both patients and staff were included. A good example included a pharmacist, IT lead as well as communications and a strong patient voice	• Lack of preparation for initial peer assist event • **Meeting regularly was challenging** as it required motivation and coordination • **Not having a route through which actions and successes were fed back to the unit's senior team** which impacted on continuing momentum
Champions and leaders **Green: 9** **Amber: 3** **Red: 2**	• Units appointed champions and leads internally who had **credibility, authority and a voice** – these champions whether patients or staff might have been **self-appointed but were endorsed** and acknowledged by the senior team • **At least one of the champions in each of the units was a consultant nephrologist supported by a senior nurse** both of whom had capability, authority and access to the senior team • The units **believed in the principle that patients and members of the wider multidisciplinary team had**	• **Lack of endorsement from the wider team resulting in isolation** and inability to champion • Where the champions were **junior nursing staff** who worked in a hierarchical way there were challenges in engaging the medical staff and other members of the multidisciplinary team all of whom had competing priorities

	leadership skills to become champions but required support to achieve this **A willingness to look beyond traditional hierarchies** and use leadership skills in both patients and staff Units attempted to provide an infrastructure of **regular meetings which the champions coordinated,** providing updates with the ultimate aim of engaging a wider network of patients and staff	
Senior ‘buy in’ **Shared values and common purpose** **Green: 7** **Amber: 5** **Red: 2**	**Endorsement by the Clinical Director and/or the senior management team** of the programme as one of the priorities for the unit Able to articulate a vision for change **Support of the senior/lead nurse**, advocating the key messages of the programme and supporting staff in delivering them These leaders were **not hands on in delivering the programme but ensured that it was incorporated in agendas and meetings and seen as important** A strong multidisciplinary team approach	**Strong commitment and energy at a nursing and patient level** to participate in the programme. However the programme did not appear to be strongly endorsed by the medical lead or senior nurse Collecting patient measures although acknowledged as worthy was regarded as **more desirable than essential**
Quality improvement	Good understanding of **starting small and building incrementally**	Challenges centred around the time and sustained effort it takes to implement data

Green: 7 **Amber: 2** **Red: 5**	• An understanding about building on skills and knowledge of what has worked before and not to repeat mistakes • Not necessarily a formal Plan Do Study Act (PDSA) cycle but an informal **discussion at working group level that was documented and reflected upon** • *Your Health Survey* was collected from a variety of different patient cohorts, such as a single clinician's outpatient clinic, a transplant population or a bay of haemodialysis patients • Units **used the learning from the initial collection to spread to other parts of the pathway** – for example, one unit surveyed the transplant population in outpatient department and then surveyed the in-centre haemodialysis population, whilst others concentrated on capturing patients from all parts of the pathway (transplant, peritoneal dialysis, CKD and haemodialysis) through their outpatient department	collection change • Units were not necessarily conversant in a Quality Improvement approach and **saw it as time consuming and potentially unnecessary work** • Initial benchmarking data was collected but it wasn't part of a sustainable process based on incremental change
Co-production **Green: 8** **Amber: 2** **Red: 4**	• Units attended the events with **patients in equal numbers**, appointed a patient lead within the working group and included patients in implementation plans • Worked with patients and **developed the more traditional role of volunteer into something that was integral to the delivery and sustainability of the programme** • Used peer supporters to support the implementation of	• Included patients in the peer assist events and encouraged involvement in limited internal meetings and implementation plans but reflected **a more traditional public and patient involvement (PPI) approach** • Challenges cited in developing a co-productive approach reflecting a need for

	patient measures within the haemodialysis department and worked closely with local Kidney Patient Associations alongside multidisciplinary team members to hand out surveys and discuss with patients the benefits of being involved	both staff and patients to be upskilled • **Current systems, processes and hierarchies not supportive of this approach** • Patients are keen to be involved in initiatives but their time is often **restricted through treatment regimens and periods of ill health**
Engagement of the whole team **Green: 7** **Amber: 0** **Red: 7**	• Understanding that to build sustainability from the beginning the **wider team needed to be engaged early on** • **Used presentation of the benchmarking data as a means to engage** the wider team and discuss future spread • **Different forums were used** such as **multidisciplinary team meetings, Clinical Governance or Kidney Patient Association meetings** • Meetings tended to have senior members of staff in attendance so additional workshops and sharing of the data were welcomed by staff	• **The lead working in isolation** without clear understanding and endorsement from the wider team • Most of the programme leads pointed out that **engaging their consultant colleagues was the most challenging** element as they had different priorities and interests • It was **suggested by some teams that they were already doing this and they did not think collecting measurement data added value** • Although meetings and workshops were offered and at times accepted they tended to include the smaller working group rather than the larger team • Some unit teams seemed to **lack the confidence and authority to promote this**

		work internally hence lost energy and momentum
Communication **Green: 7** **Amber: 1** **Red: 6**	• Valued communication as a vital part of the wider engagement and spread • **Units participated in the monthly calls to share learning** and were keen to **promote this learning through the** bulletins that were regularly produced by the programme • **Liaison with the Trust communications** team to promote the programme through internal Trust bulletins resulting in an article **and photo in the local press outlining the project** and the involvement of patients • **Abstracts developed and accepted for national kidney conferences** where teams were able to present their work to others. • One unit supported by their communications team developed a **DVD of patient stories and experiences that is now shown in the outpatient department** where the patient measures are collected and then discussed within the consultation	• Units, although encouraged, found it **challenging to use the communication channels made available** to them • **Time-constraint was quoted as the main reason** alongside lack of skills to convey key messages • Working with the **Trust communications team was not common practice** and the units didn't feel they had a story that was newsworthy • It was evident that this element requires driving and coordinating though this is not always seen as important

1.3 Key themes

From the principal characteristics described in Table 4 there are a number of themes that emerge that can be used to further categorise the barriers and enablers to routinely collecting these measures. These themes have been described in a variety of important reports such as the Francis Inquiry (15), Ideas into Action: Person Centred Care in practice (6) and most recently published in the University of Leicester's independent evaluation of the feasibility of using the PAM in NHS England (16). All of these align with the NHS change model cited earlier in the report with the overarching theme of a shared vision in eliciting transformational change.

The themes are outlined below:

Positive culture, common values and strong leadership
Senior level support at unit level was recognised as being a main theme across the most successful implementers. This was more than just attending meetings but about the senior leadership consistently advocating the key messages of the programme and being responsive to staff concerns. A proactive consultant lead within the unit shaping the vision was paramount to the success or failure of programme implementation.

Engagement with wider team
Engagement with the wider team and embedding patient reported measurement within unit plans proved challenging and required a lead-in time and sustained effort which cannot be underestimated. The better performing units started the implementation of these new measures because it was something they believed in and wanted to do, yet understood that progress was a 'slow burn' and that they were at the beginning of the journey.

Difficulty in engaging the whole team was cited consistently as being a real challenge – especially amongst consultant colleagues. The better performing units were those that invited the PCCF to run workshops and share data pertaining to the patients that they were treating. There was a sense of responsibility that came with knowing a patient's symptom burden, particularly when patients had cited that they had overwhelming depression or anxiety alongside their level of activation.

The units within cohort two, although benefiting from the learning of cohort one, still required a lead-in time comparative to that of cohort one. This stepped approach was not necessarily of benefit as engagement was lost with those units in cohort two waiting to participate. Other priorities took precedence in this time, resulting in many units originally designated to be part of cohort two being unable to start when the time came.

Alignment with wider priorities – understanding of the bigger picture and context with a longer-term aim and vision

Alignment with wider priorities was evident in the units which were more successful, for example the units had an agenda of person-centred care and the Five Year Forward View as a broader strategic aim, perhaps denoting the positive culture of the unit. There was an understanding that the collection of patient reported measures could be the foundation of transformational change.

A change in professional roles and behaviours

Feedback received from some unit staff suggested that they were practising person centred care and therefore did not need to measure patient reported outcomes in order to change their practice. This was especially pronounced in units which performed less well in collecting data routinely, and which also suggested that there was insufficient time in clinics and consultations for additional conversations with patients that might use up the limited time available. Workforce issues such as vacancies and sickness, especially amongst nursing staff were cited as being a barrier to collecting the surveys and unless one person took responsibility (invariably nursing staff) and coordinated implementation it was not likely to happen.

Sustainability

Those units that performed less well at implementation approached it more as a short-term project with a beginning and an end. Additional staff resource allocated to the implementation of surveys seemed to have a positive impact on collection. One unit gained internal funding through a separate project and combined the resource to aid implementation of *Your Health Survey*, whilst another unit put in additional resource to the outpatient department to help support implementation. Both units recognised that this approach was not sustainable.

Lack of resource was cited as one of the main reasons for being unable to sustain multiple collections. The workforce was stretched and did not have the capacity to take on anything new that might require change in practice and behaviours. There appeared to be little available time or capability for the whole team to prepare for how this might be implemented. This often meant that people were working in isolation and/or undertaking additional work as part of traditional processes that were then deemed not sustainable.

Units that performed well were those that had a senior consultant lead who endorsed this as important and supported introducing and testing out different ways of working. It was also very useful to have a senior nurse as part of the core team in order to maintain consistent key messages and credibility across staff and patient groups.

IT systems and data flows

Teams that had a lead with an interest in IT understood the importance of embedding tools and measurement into clinical IT systems to regularise and sustain their use. IT systems were commonly cited as being a barrier to embedding the collection of this measurement as routine. The survey was introduced on paper which was completed and then couriered back to UKRR for analysis. Several units found that if they gave the survey to patients to fill in at home they did not complete it. More success was experienced when the survey was given to the patient to complete in the hospital environment.

Each unit has a different IT renal system and the providers require additional budget to make changes to screens which was not seen as a priority. Data flows and timings of data flows from UKRR to renal units were cited as a barrier to collection and re-survey, as patient level results were not available in real time. This did not lend itself to incorporating patient measures into consultations with patients, leading to a change in practice and therefore a need for a follow up survey. Many clinicians did not want to re-survey patients when they still had not received previous results or the time lapse between surveys and results had been too long. Additional demands on staff to input survey results into their own IT system manually proved challenging for reasons of time and resource.

Real time calculation of PAM scores and levels were offered via a macro-based excel spreadsheet but required manual input which again proved challenging within an outpatient environment.

Additional screens were developed on the patient portal PatientView to enable patients to access their PROM results. The uptake of this by patients was limited and varied from unit to unit.

Putting patients first – involving patients in all that is done

The culture change required to embed person centred care approaches requires a different perspective of the health care professional – that of the patient relationship. Learning from the programme suggests that patients actively involved at unit level and participating as a co-chair or within the working group aided the success of the programme. Patient champions held their professional colleagues to account and were often the driver behind the programme at local level.

Survey fatigue was a barrier, especially amongst haemodialysis patients who are often asked to complete several lengthy, complex surveys. An issue recurrent across all units and with all patients, especially haemodialysis patients was that they fill in several surveys and never receive any feedback. The *Your Health Survey* was seen purely as a measurement and not as a tool to inform practice in those units that performed less well. In several units, once feedback on data had been given to both patients and staff however, there was an understanding of the benefits to collecting the data.

> *"I have been wanting to talk about this stuff for so many years but never dare bring it up – this is what is important to me"*

Patient

> *"I now get it - patient activation is the missing link"*

Senior nurse

> *"I've been banging on about this for years but a fresh face with data that is real has such an impact"*

Consultant

System capacity and processes

Participating in more than one change programme or other national projects was confusing and burdensome for the participating units, even though overall key messages may be aligned.

The TP-CKD programme used a Quality Improvement approach with no additional resource to embed the collection of these measures in a sustainable way. Other projects used research methodology and utilised research nurses which was in direct contrast. Some of the more successful units managed both, leading to an overall increase in *Your Health Survey* collection than would not have otherwise been realised.

Section 2

This section uses the data collected by the TP-CKD programme to describe the potential association between kidney patients' levels of knowledge, skill and confidence (their activation level as measured by the PAM), QoL (EQ5D-5L), symptom burden (POS-S renal), demographic and biomedical parameters.

2.1. Methods

Your Health Survey was developed by the TP-CKD measurement workstream and comprised three previously validated self-administered surveys (Appendix 1):

- Five questions on QoL (EQ-5D-5L (4))
- 17 questions on symptoms (POS-S renal (3))
- 13 questions on the knowledge, skills and confidence of the patient in managing their health (PAM (1))

The EQ-5D-5L questions use a scale from one to five representing increasing difficulties with performing 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 POS-S renal questions use a scale from zero to four representing increasing severity of symptoms (0=not at all, 1=slightly, 2=moderately, 3=severely, 4=overwhelmingly). For the purpose of this report symptom burden is grouped as follows: 0 and 1 = absent/mild; 2, 3 and 4 = moderate/severe/overwhelming.

The PAM 13 item scale enquires about patient's knowledge, skills and confidence in self-managing their health and then assigns an activation score based on responses. Patients can respond to the PAM questions with 1=strongly disagree, 2=disagree, 3=agree, 4=strongly agree. This PAM score corresponds to a level of activation. The four levels are described in Figure 3.

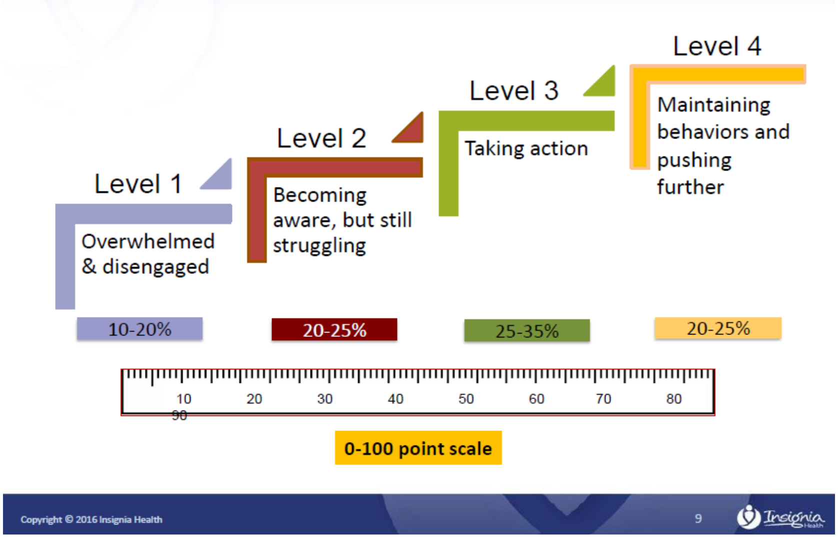


Figure 3: Description of PAM levels

Statistical Analysis

The survey data is summarised in descriptive statistics. PAM score is presented as either median or categorised into four PAM levels. Median is used rather than the mean because it is less affected by outliers or skewed data and is usually the preferred measure of central tendency when the distribution is not symmetrical.

The PAM score is also presented by different demographic variables such as age, sex, deprivation group and modality; it is also compared against PROMs, to see if there is an association between patient activation and symptoms burden or QoL outcome.

About seven percent of participants did not complete the PAM section of the survey, therefore their PAM score could not be constructed. These participants are still included in the overall analysis, but are excluded in any analysis involving PAM scores.

PAM score has also been investigated against different biomedical markers that represent patients' health outcome indicators, including haemoglobin, calcium and phosphate.

To investigate whether there was an association between a patient's activation and their biomedical markers the *Your Health Survey* data was linked to the UKRR dataset using NHS number, date of birth and residential postcode.

The UKRR extracts biomedical data quarterly. To ensure a meaningful comparison, the biomedical data was linked to the *Your Health Survey*s collected within the same quarter, or the adjacent quarter if the data from the same quarter was not available. The UKRR datasets have been validated up to 31 December 2016, therefore only surveys collected up to 31 March 2017 could be included. Linkage was possible for 1,844 of 3,325 patients (55%) surveyed.

Statistical tests are occasionally used to determine the significance of the hypothesis statements with a p-value; a small p-value (typically $p \leq 0.05$) indicates strong statistical evidence to support the hypothesis statement.

2.2. Patient demographics

14 renal units in England submitted data as part of the TP-CKD programme with 3,325 patients completing and returning a first survey between March 2016 and December 2017. The majority of patients (58.8%) completed the survey on their own with 15.2% receiving help from staff and 18.7% completing the survey with help from a friend or relative (Table 5). The majority of surveys were completed at the renal unit or clinic setting (73.3%), with a smaller proportion completed at home (21.5%) (Table 5).

Table 5: Patient demographics

Patient descriptions and demographics	Number	Percent (%)
Assistance with survey completion		
Own	1,990	58.8
Staff	506	15.2
Friend/relative	622	18.7
Missing	207	6.2
Total	3,325	100.0
Completion of survey		
At home	714	21.4
Renal unit	2,039	61.3
Clinic	402	12.0
Missing	170	5.1
Total	3,325	100.0
Age distribution		
18 to 24	55	1.6
25 to 34	171	5.1
35 to 44	298	8.9
45 to 54	579	17.4
55 to 64	710	21.3
65 to 74	746	22.4
75+	755	22.7
Missing	11	0.3
Total	3,325	100.0
Sex		
Male	1034	56.1
Female	690	37.4
Missing	120	6.5

Patient descriptions and demographics	Number	Percent (%)
Total[4]	1,844	100.0
Treatment type		
Haemodialysis	921	27.7
Pre-dialysis	320	9.6
Transplant	617	18.6
Peritoneal dialysis	51	1.5
Missing	1,416	42.6
Total	3,325	100.0

66.4% of patients completing the survey were older than 55 years of age with only 1.6% completing the survey in the 18–24 years age group. This demographic is similar to the age profile of prevalent renal replacement therapy patients in the 2017 UKRR Annual report. The majority of returns were from in-centre haemodialysis (27.7%) and transplant patients (18.6 %). Missing data accounted for 42.6% of the modality returns as this was not collected at the start of the programme.

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[4] The total number for sex is less than the total number of surveys analysed because sex was not collected on *Your Health Survey*. This information was retrieved from the UKRR database. Linkage was possible for 1,844 of 3,325 patients surveyed.

2.3. Results: Patient Activation Measure (PAM)

This section reports the patient activation scores and levels found across the patient population, relating to age, sex, modality, deprivation, renal unit, symptom burden (POS-S renal) and QoL (EQ5D-5L).

Overall (Figure 4) 25% of patients surveyed self-assessed as level one, 18% as level two, 33% as level three and 17% as level four with 7% missing data. This supports the findings of a study by Hibbard *et al*. which estimated that between 25% and 40% of the population have low levels of activation (levels 1 and 2) (14).

Level one is described as a patient being overwhelmed and passive recipients of their care. Level four is described as patients who are able to maintain responsibility for their care even under pressure from stress or health crises.

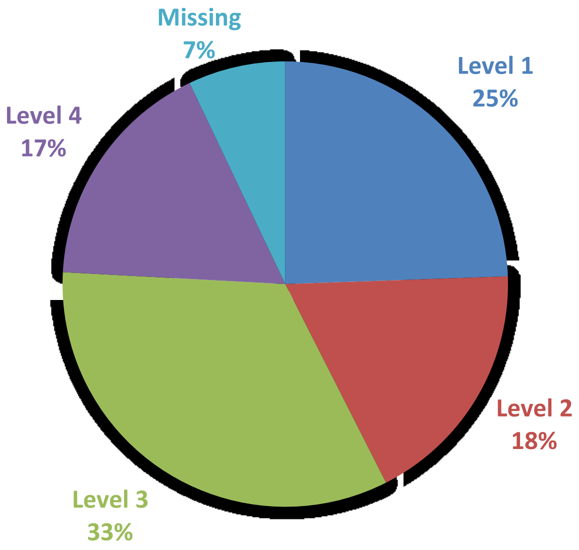

Figure 4: Overall PAM levels

Figure 5 shows that activation scores were highest in respondents aged 25–44 years, activation in the main decreasing with increasing age. There were no significant differences in the distribution of PAM levels between males and females.

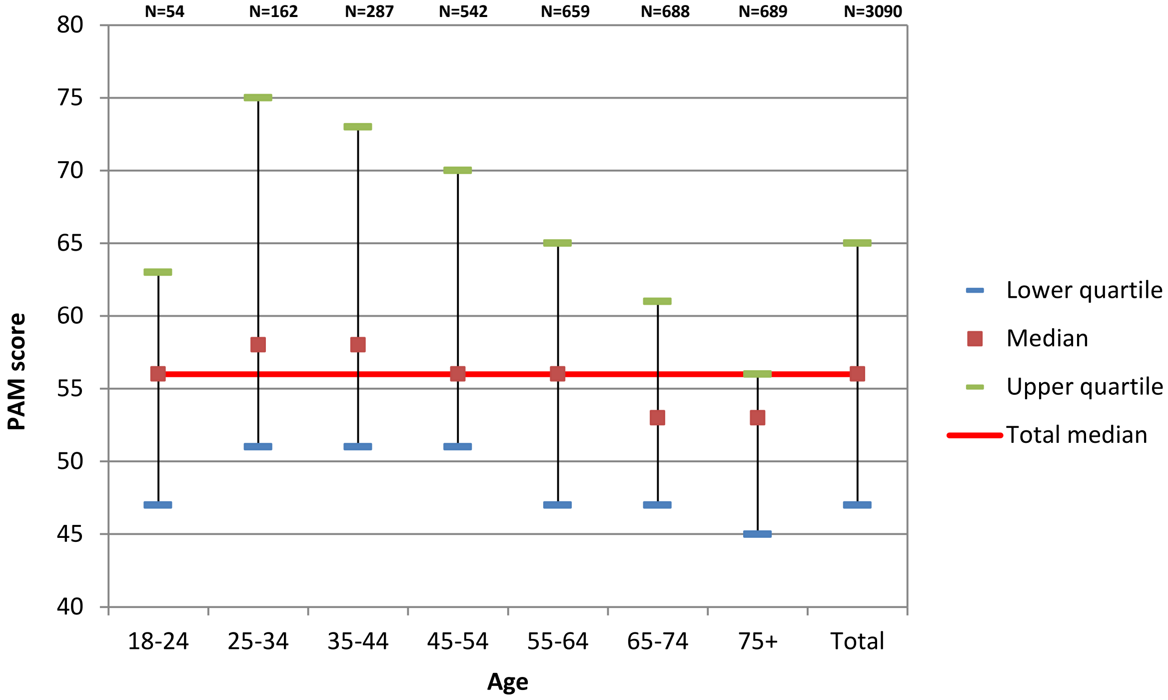

Figure 5: Median PAM score by age

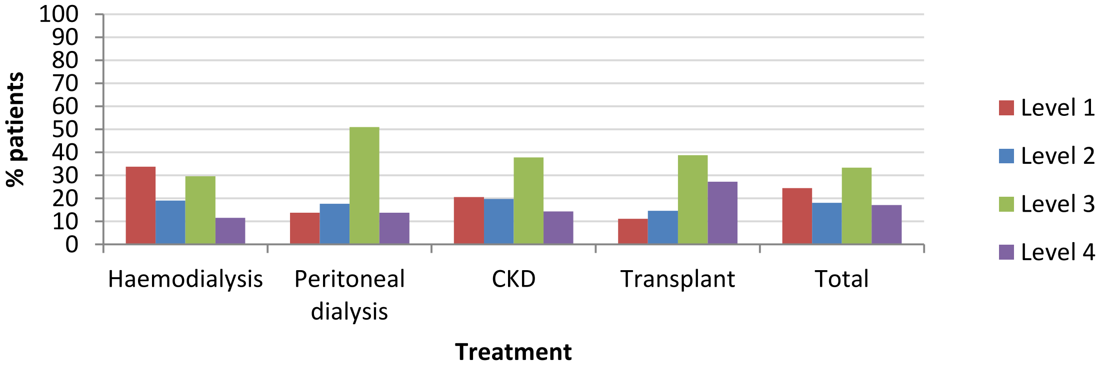

Figure 6: PAM levels by treatment

Haemodialysis patients had significantly lower activation levels (53% at level one and two) compared to those within peritoneal dialysis, CKD and transplant populations (32.0%, 40.0% and 25%), (p < 0.00001). This result may reflect the self-care nature of transplant, CKD and peritoneal dialysis patients, though there are other major differences between these groups including age and comorbid burden. Pre-dialysis care and education and time on dialysis may also impact on a patient's knowledge, skills and confidence in self-managing their care. A recent study supports these findings (17), stating that haemodialysis patients have the lowest level of activation and patients with the lowest levels of activation report the worst symptoms.

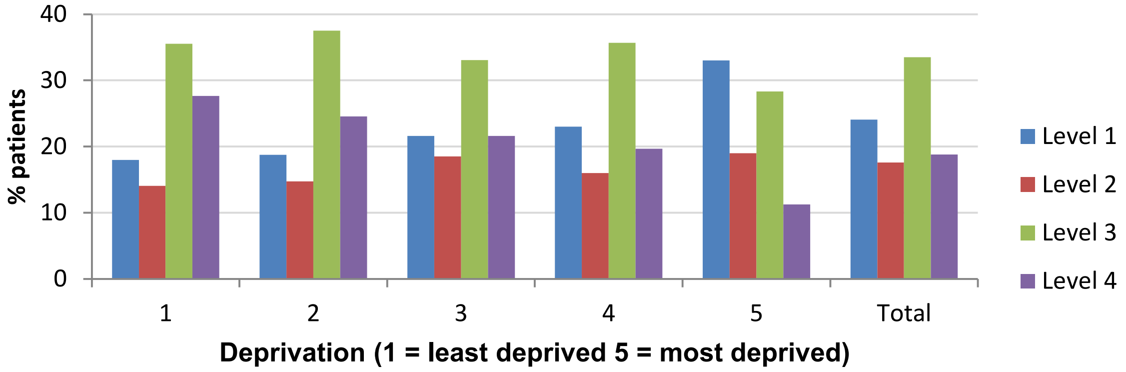

Figure 7: PAM levels by deprivation

The assessment of deprivation is based on the Index of Multiple Deprivation (IMD score) calculated using the person's post code and scored from one (least deprived) to five (most deprived). 63.2% of the least deprived patients (n = 233) had a high activation level (3 or 4) compared with 39.6% of the most deprived patients (n = 414). (Figure 7, p<0.001).

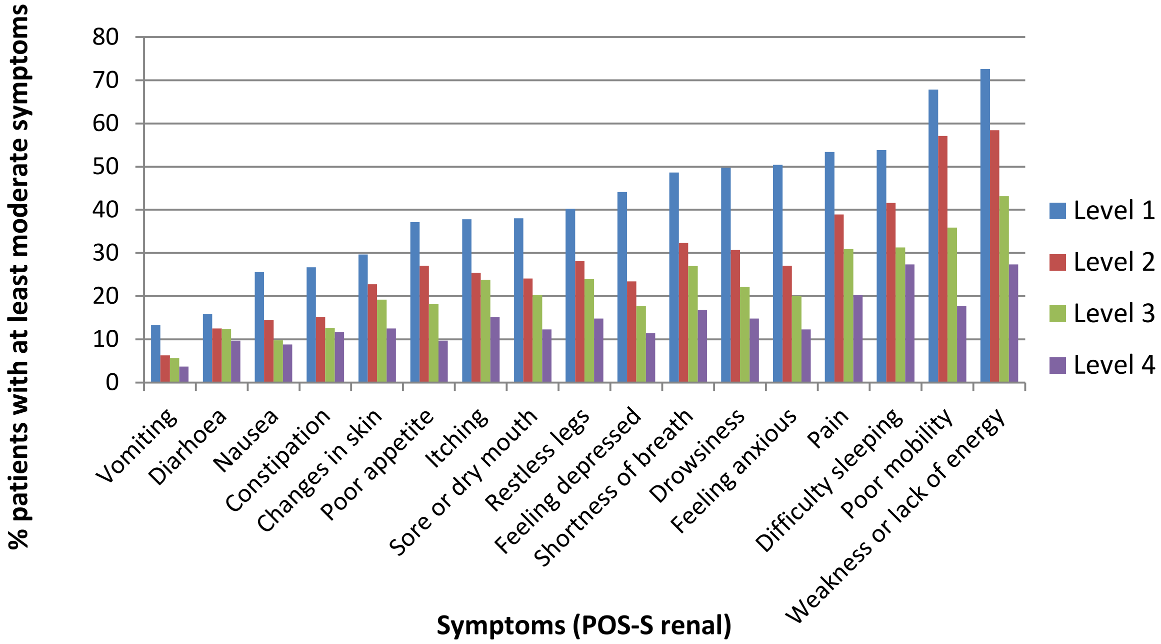

Figure 8: PAM levels by symptoms (POS-S renal)

Figure 8 shows a close relationship between symptom burden and activation level. Overall increasing levels of activation were associated with decreased symptom burden. This was true for each individual symptom as well as symptom burden overall. More respondents (37%) at a lower activation level (levels 1 and 2) than those with a higher activation level (3 and 4, 20%) reported at least moderate symptoms across all of the 17 POS-S items (p<0.001).

Further research is required to explore how these relationships are modified by age, sex and modality.

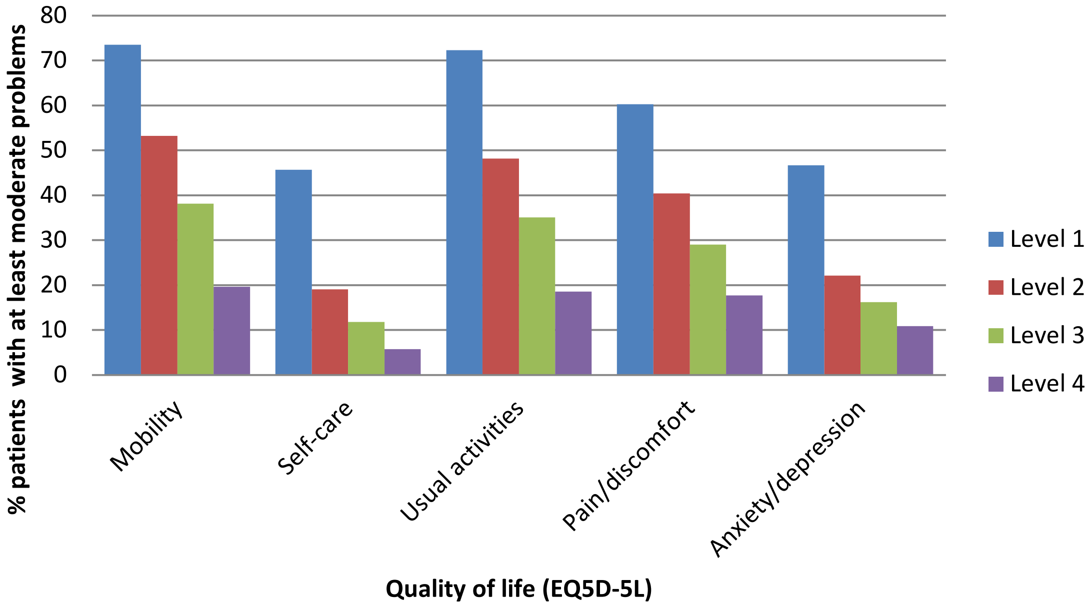

Figure 9: PAM levels by quality of life (EQ-5D-5L)

Figure 9 shows a close relationship between activation level and the EQ5D-5L QoL domains. Increasing levels of activation were associated with better QoL in all domains. Respondents at activation levels 1 and 2 (70%) were more likely to report at least moderate problems with mobility, self-care, usual activities, pain and anxiety than those at activation levels 3 and 4 (41%) ($p<0.001$) (see appendix 2 for EQ5D-5L by modality).

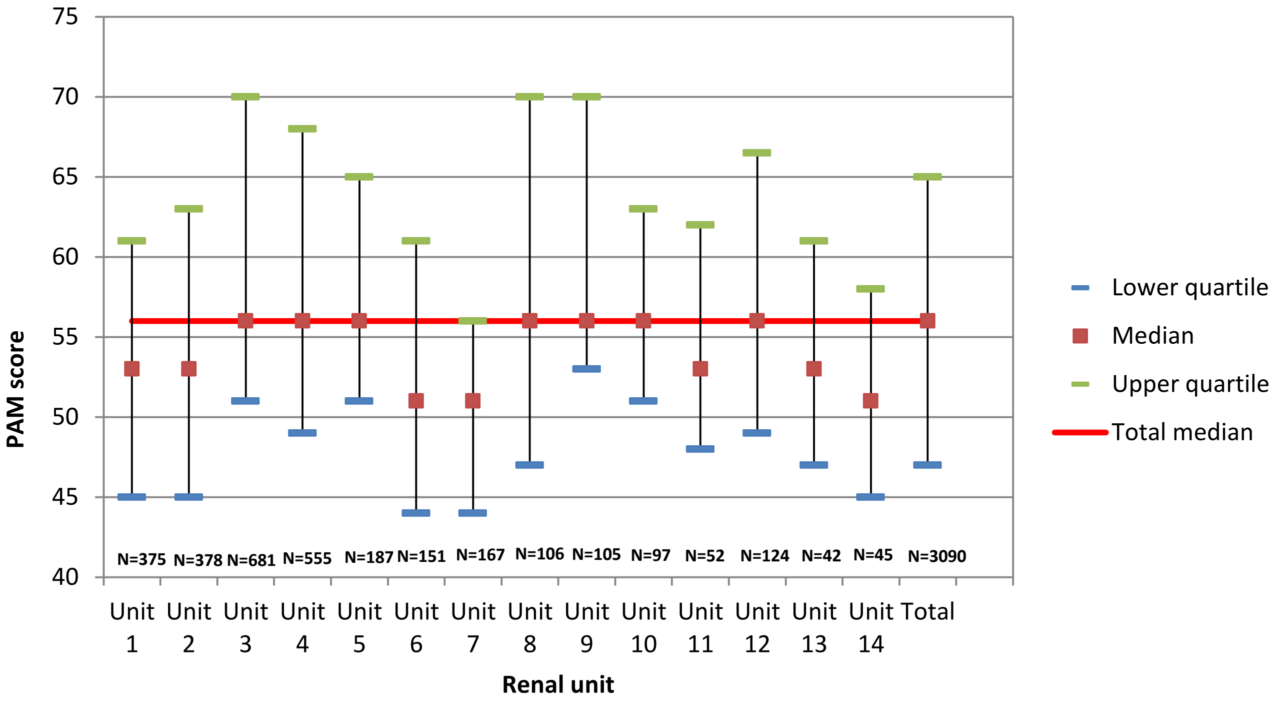

Figure 10: Median PAM score by renal unit

There were unit variations in patient activation scores[5] but comparison of results between renal units must be carefully interpreted because of major differences in case-mix, particularly in relation to modality which appears to be a major influence on activation level (Figure 6). Furthermore, patients who completed the survey may not have been representative of all unit patients.

There appeared to be no simple relationship between the RAG ratings of units (see Table 3) and the median unit PAM scores (Figure 10).

Biomedical markers by patient activation (PAM)

To investigate the association between a patient's activation and their biomedical markers *Your Health Survey* data was linked to the UKRR dataset using the NHS number, date of birth and residential postcode. The UKRR extracts biomedical data quarterly. Therefore, to ensure a meaningful comparison, the biomedical data was linked to the *Your Health Survey*s collected within the same quarter, or the adjacent quarter if the data from the same quarter was not available.

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[5] If the distribution is normally distributed, the mean is equal to the median. The reason why we chose to use median rather than the mean is because the distribution is asymmetrical, and median is less affected by outliers.

There was no association between a patient's activation level and their phosphate, calcium and haemoglobin biomedical markers, overall or by modality, potentially supporting the idea of there being a disconnect between biomedical guidelines and markers and what patients report as being important to them (for an example of data see Appendix 3).

2.4. Results: Clinical Support for Patient Activation (CS-PAM)

CS-PAM measures the level of support by clinicians for patient activation. It was conducted independently to the PAM survey, using either a paper or an online questionnaire and was not linked to the patient data collection exercise.

Across the 14 units, approaches to CS-PAM varied. All units developed a way of collecting CS-PAM data from the staff they identified as relevant, suggesting that it is possible to collect CS-PAM data, which can then be used as a reflective tool and to identify training and support needs.

All renal unit staff were invited to participate in the CS-PAM. Completed CS-PAM returns from the 14 units ranged from six to 65 of an estimated 250 total unit workforce and were therefore not necessarily representative of all staff groups. In the main nursing staff and allied health professionals completed the survey.

Objective 3 of this programme will investigate whether a change in clinician activation influences any improvement in patient activation.

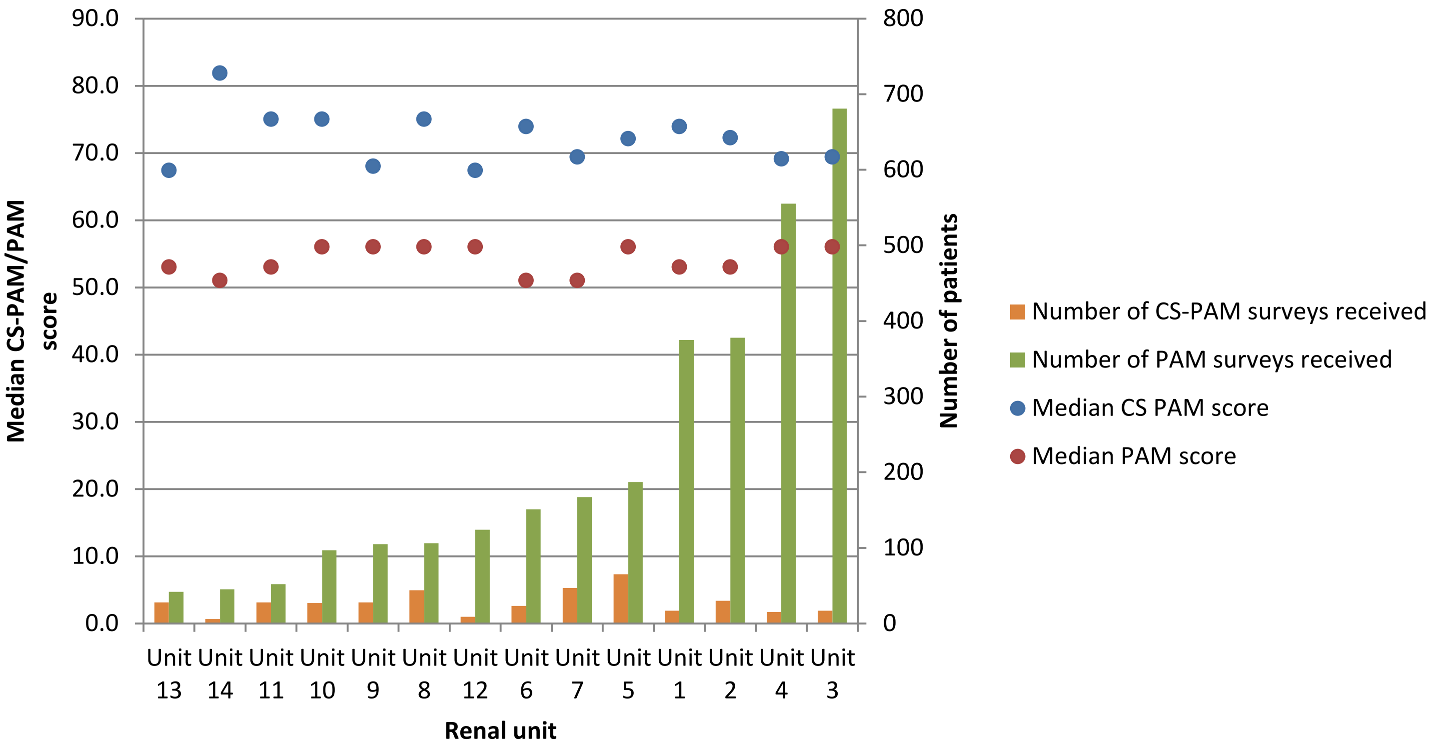

Figure 11: median CS-PAM/PAM score by renal unit

There appears to be no clear association between clinician support and patient activation levels, i.e. a higher level of clinician support within a unit does not seem to associate with higher levels of patient activation (Figure 11).

2.5. Results: PAM re-surveys

Patients were re-surveyed in six of the 14 units from four to six monthly. The results shown in Table 6 are based on changes between the first and second PAM survey only.

Only 8% (276/3,325) of total respondents had a third survey and 2% a fourth survey (83/3,325). As this amount is not representative and therefore open to bias, these results are not included in this report. The total number of re-surveys received was 842. The total number of patients who had a PAM score in first and second survey was 743 and is reflected in the table below.

Table 6: PAM re-surveys

PAM level	No. of patients who have a PAM score on the 1st and 2nd survey	Median PAM score change	Inter-quartile range (IQR)	% Declined	% Un-changed	% Improved
Level 1	188	3	-1 to 10	27.1	11.2	61.7
Level 2	132	2	-4 to 7	34.8	9.8	55.3
Level 3	279	0	-7 to 5	46.6	19.7	33.7
Level 4	144	-5.5	-22 to 0	63.2	20.1	16.7
Total	**743**			**42.8**	**15.9**	**41.3**

Table 6 shows that the greatest improvement between first and second surveys were in PAM levels one and two (61.7% and 55.3%) with a median score change of three and two respectively. In contrast, levels three and four showed an improvement in only 33.7% and 16.7% with a median score change of 0 and -5.5. This fits with the published literature showing most gains occur within patients at PAM levels one and two (18).

It must be noted that any PAM changes shown in this data are not in response to targeted interventions. It is plausible that simply completing a PAM survey could be an intervention in itself as the process of patients reflecting on the questions may help elicit a change in beliefs around their health status. It should be noted, however, that the changes that did occur are significantly less than that through interventions specifically designed to improve activation where a 10 point change is often realised.

Renal units are currently very focused on the bio-medical elements of care and are less focused on the psychosocial/behavioural elements. Further analysis is required including collecting longitudinal data from the same people over time to understand their changes in activation and outcomes following such interventions.

We have considered the statistical phenomenon 'regression toward the mean' that can make natural variation in repeated data appear to look like real change (19). This could have played a role for the change that we observed in the re-survey data, however there could also be other factors changing the attitude of the patients. It is difficult to quantify the impact at this stage. In future re-survey study designs, the regression toward the mean effect could be identified by including a randomly allocated control group, so that the true effect of an intervention can be measured.

As previously explained the PAM score is on a 100 point scale. Recent evidence from the UK (20) has shown a correlation between high activation scores and lower hospital admission rates, and that increases in the PAM score within a level are important. It is therefore important to report the PAM score in addition to the level.

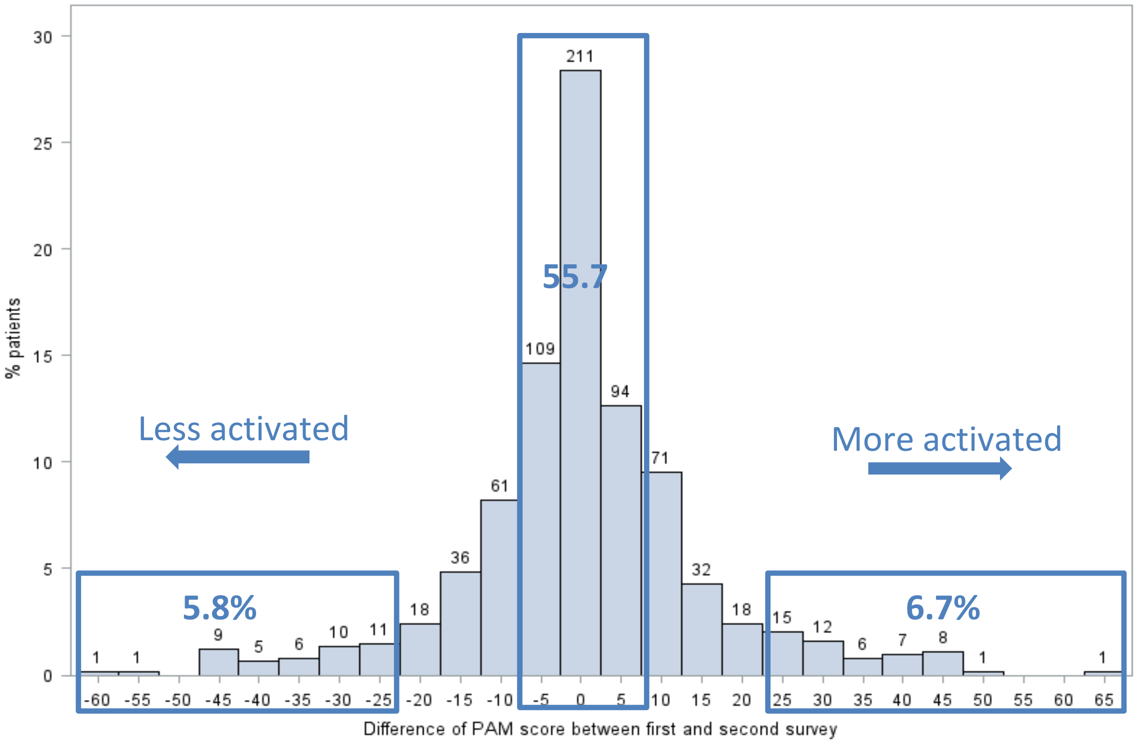

Figure 12: Overall distribution of the difference in PAM score between first and second PAM surveys

The figure above shows the overall distribution of the difference in PAM score between the first and second PAM surveys. As seen in the peak of the figure, 55.7% of the patients had less than ten score points difference and 12.5% of patients had more than 20 score points difference between their first and second PAM score; in other words, only a small proportion of patients experienced dramatic differences in activation after four to six months (the time between surveys varies amongst patients). The overall distribution is fairly symmetrical, which suggests that the overall attitude change for the majority of the population sampled did not change.

2.6. Limitations

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

It is difficult to interpret data which included multiple modalities and further research will be required to look at this data broken down by treatment type in more detail.

A further limitation is that *Your Health Survey* was only available in English within this programme and as a paper copy. This approach has the potential to limit accessibility for those for whom English is not their first language.

A 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 individual answers and different approaches to implementation may have created bias. For example, handing out the survey via patient volunteers may have a different explanation and therefore different result than if the request to complete the survey had been made by a health care professional.

Conclusion and recommendations

TP-CKD aimed to establish the feasibility of routinely collecting PAM and PROMs in kidney patients. 14 units participated in the programme with 3,325 patients completing at least one survey, collecting patient reported measures including assessment of patients' knowledge, skills and confidence in self-managing their health (the Patient Activation Measure® PAM® (1)), symptom burden (POS-S renal (3)) and QoL (EQ5D-5L (4)). These instruments were embedded into a survey tool known as *Your Health Survey*.

Renal units were taken through the peer assisted programme by a PCCF, focussing on nine key stages of implementation aligned to the NHS Change Model. Units were free to decide the patient cohort in which to implement *Your Health Survey*.

There is some correlation between success in achieving routine collection of patient measures and unit adoption of the pre-defined characteristics likely to facilitate successful engagement with the programme. These include:

The peer assist model
Participating in components of the peer assist model such as 30-60-90-day plans, working groups and sharing of learning through blogs and case studies provided a framework and structured approach for units. This enabled units to set their own objectives and engage with peers voluntarily and provided a structure for building capacity to embed outcome measures.

Senior level support at unit level
Proactive leadership was paramount to the development of a local TP-CKD 'vision'. Successful units required senior leaders to act as advocates of the key messages of the programme and respond to staff concerns.

Engagement
Embedding patient measures within the unit through engagement of whole MDT teams required a commitment to the programme in the face of competing priorities and clinical teams owning the responsibility that comes with knowing a patient's results, and addressing the results appropriately.

Alignment with wider priorities
TP-CKD fitting in to the wider strategic view of the unit, and clinical teams recognising the collection of patient reported measures as the foundation of change.

Common characteristics that supported a sustainable approach to collecting patient reported measures included:

Allocating sufficient staff resource

- Making TP-CKD 'the way we do things round here' in order to overcome time and resource barriers
- Establishing a communication channel between staff and patients
- One person to be given responsibility to coordinate implementation

IT systems and data flows

- Understanding and acting on the importance of embedding tools and measurement into clinical IT systems
- Successful survey completion was more likely in the hospital environment
- Making data available in real time

Co-production – involving patients

- Involving patients as board members, locally within working groups and as champions provided a perspective that was invaluable
- Patients actively involved at unit level and participating as a co-chair or within the working group
- Communicating *Your Health Survey* as a tool aiding person centred care rather than simply a measurement

Whilst it is important to note the characteristics for success, and the facilitators and barriers to achieving those characteristics, it is also important to consider the unit approaches to overcoming challenges which were common to those units who went some way to achieving routine collection and use of patient measures. These included:

- Inviting the PCCF to run workshops
- Sharing data pertaining to the patients that they were treating to the wider MDT and patients
- Overcoming time and resource barriers, whether real or perceived
- Leadership

Analysis of the data shows a close relationship between patient activation, symptom burden and QoL.

For both individual symptoms and overall symptom burden, increased activation scores were associated with decreased symptom burden, with more patients at levels one and two reporting at least moderate symptoms than those with higher activation levels.

Increased levels of activation were associated with better QoL in all domains of the EQ5D-5L (4), more patients at levels one and two reported at least moderate problems with mobility, self-care, usual activities, pain and anxiety than those at activation levels three or four.

Patient activation scores vary between units, however differences in patient respondent profile makes interpretation of this variation difficult.

The data collected within the TP-CKD programme showed certain patient characteristics were associated with a patient's activation profile. Key findings included:

- Activation scores tend to decline with age
- There were no significant differences in PAM scores according to sex
- Haemodialysis patients were significantly more likely than other modalities to have the lowest activation scores (at PAM level one or two)
- Patients living in less deprived areas were significantly more likely to have higher activation scores (PAM level three or four) than patients from more deprived areas
- No correlation between patient activation and biomedical markers such as Haemoglobin, calcium and phosphate.

The UKRR has developed the infrastructure to support the collection of patient measures and provide results to patients and to clinical teams via newly developed screens on PatientView.

Further work with centres regarding how best to embed these tools within their own IT systems is required to address issues such as availability of real time data and accessibility of patient measures to those who may not have health or digital literacy.

In order to further embed patient measures into mainstream practice a number of commissioning and professional levers need to be considered. Although the role of the CQUIN and other incentives remain unclear, commissioning levers such as CQUIN, service specifications and dashboards could be considered. Further work is required to understand the differing success of incentives to influence, drive and embed change.

It is important that clinical staff and patients gain an understanding of the benefits of collecting this data and more information is required on how it may be used. This is reinforced from the qualitative feedback data from a number of respondents suggesting that using the measures increased both staff and patients’ awareness of the importance of activation. Further work is necessary to up-skill the workforce to enable them to tailor support to those patients at a low activation level and with a high symptom burden.

These assessments alone will not improve outcomes of kidney patients or other patients with long-term conditions unless healthcare professionals, in partnership with patients, use these data to guide care.

Next steps

Central to the aims of the TP-CKD programme was finding ways to empower patients and health care professionals to create new ways of working which support patients to take greater control of their health and wellbeing, greater involvement as equals in the design and delivery of new services and to achieve the personal and clinical goals that are important to them.

Whilst a number of tools to support this person-centred approach to care were identified by patients and clinicians on the TP-CKD Interventions workstream, their effectiveness and feasibility (question 3) was not assessed as part of the TP-CKD programme.

Beyond TP-CKD

In 2018, the NHS England personalised care team and the Renal Association agreed to work together on a follow-up quality improvement programme focussing on these interventions, testing their effectiveness in practice and the difference their use makes to people living with chronic kidney disease.

It is hoped this will build on the successes of the TP-CKD programme and underpin the move beyond measurement towards changing practice and improving patient outcomes.

The programme hypothesis

"Introducing a coaching intervention to clinical staff to enhance a patient's skills, knowledge and confidence (their activation) will be a driver for delivering an improvement in clinical activation, patient activation and may also be associated with improved patient outcomes"

Aims

- To evaluate the feasibility of implementing a health coaching intervention in renal units
- To understand the current interventions that are being used from the Intervention pyramid and the feasibility of implementing this within renal units
- To investigate associations between CS-PAM, implementation of health coaching and patient activation
- To investigate the effect of an intervention on PAM levels, and explore potential associations with symptoms and health related quality of life

The programme builds on the learning and knowledge from the TP-CKD programme, and focusses on a cohort of kidney patients from four renal units in England who are attending regular outpatient appointments and who are about to embark on or are making decisions about renal replacement therapy.

This next phase of the programme will be known as Transforming Participation 2 (TP2) and further information can be gained on the Think Kidneys website.

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Appendix 1: Symptoms by modality

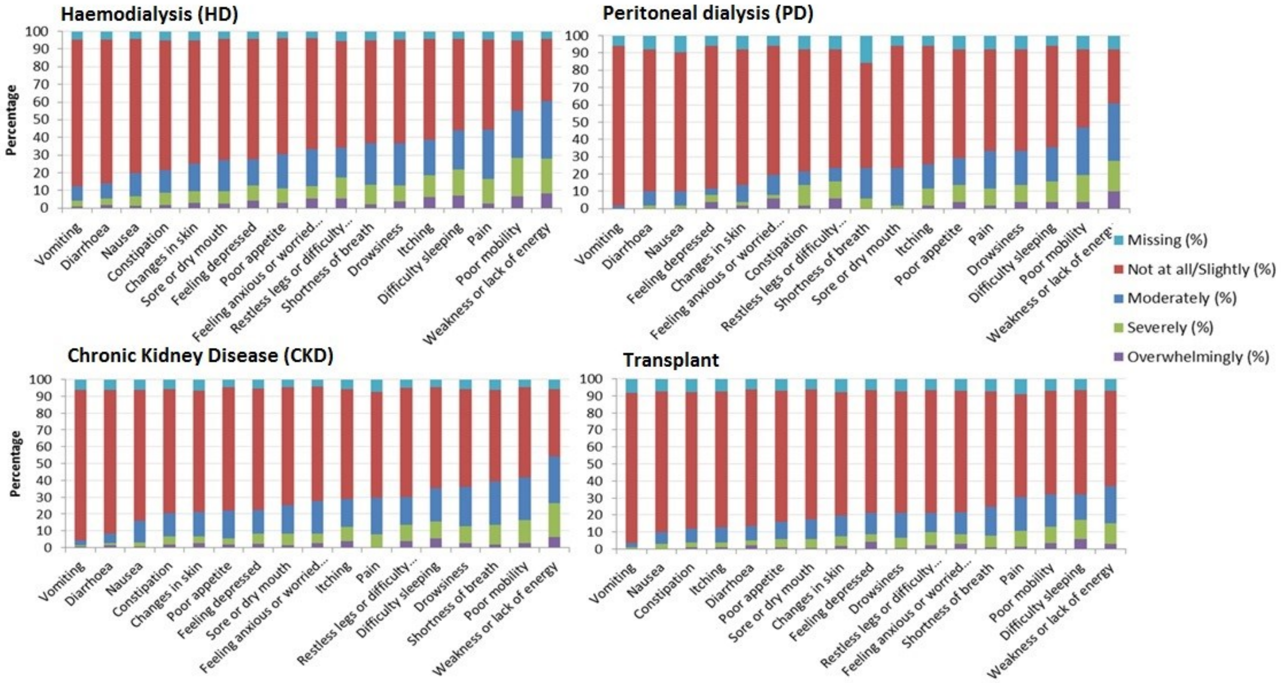

Figure 13: Symptom burden by modality

Figure 13 show the range and severity of symptoms experienced by patients on renal replacement therapy and those with Chronic Kidney Disease (CKD). The top five most prevalent symptoms varied slightly between modality, with weakness and lack of energy the main symptom across all ranging from 62% (haemodialysis), 61% (peritoneal dialysis), 55% (CKD) and 38% (transplant).

Appendix 2: Quality of life (EQ5D-5L) by modality

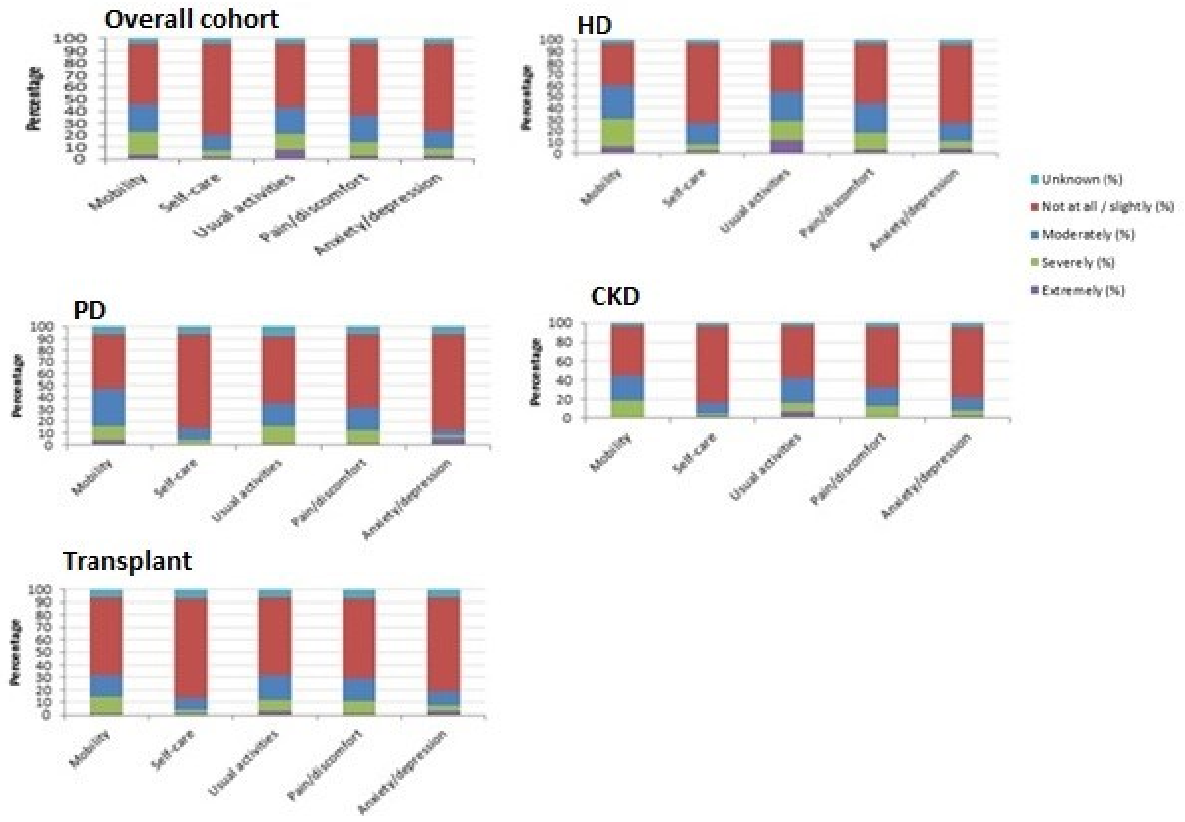

Figure 14 Quality of life (EQ5D-5L) by modality

Appendix 3: Biomedical markers by PAM level and modality

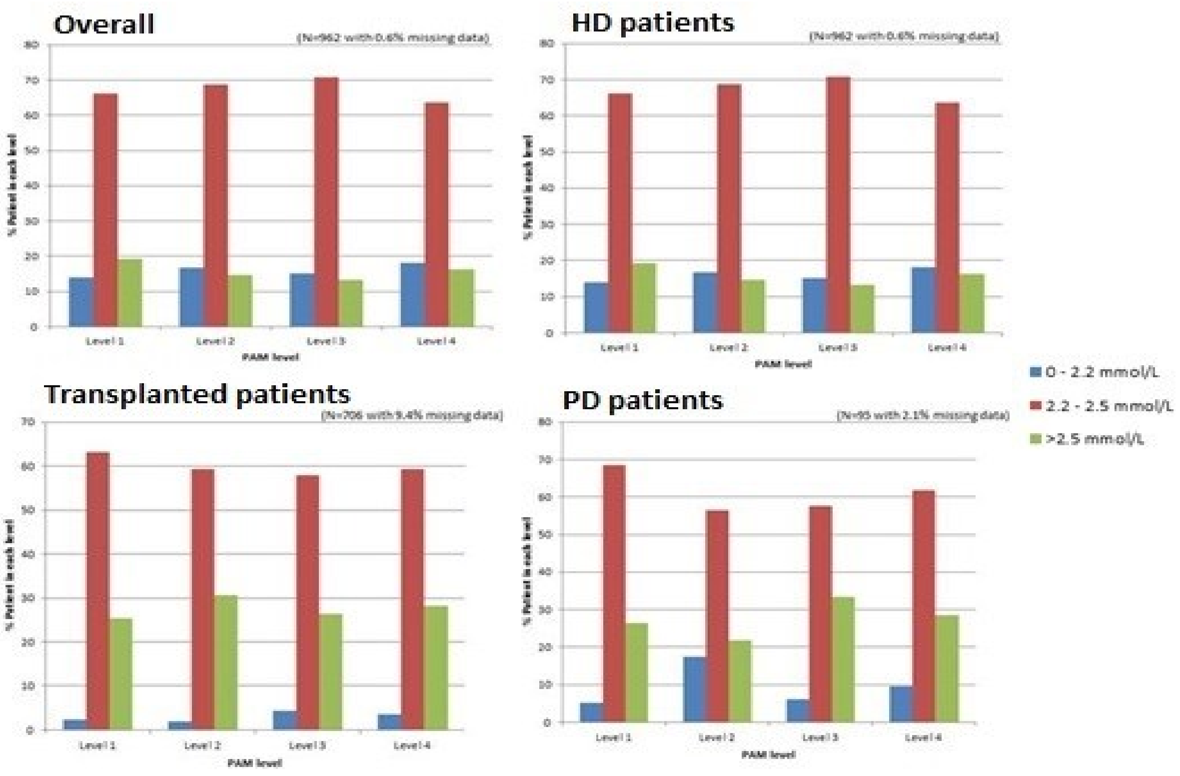

Figure 15: Calcium by PAM level by modality

Figure 15: Calcium by PAM level (RA recommendations for calcium are: CKD 3-5 normal reference range and dialysis patients 2.2-2.5mmol/L)

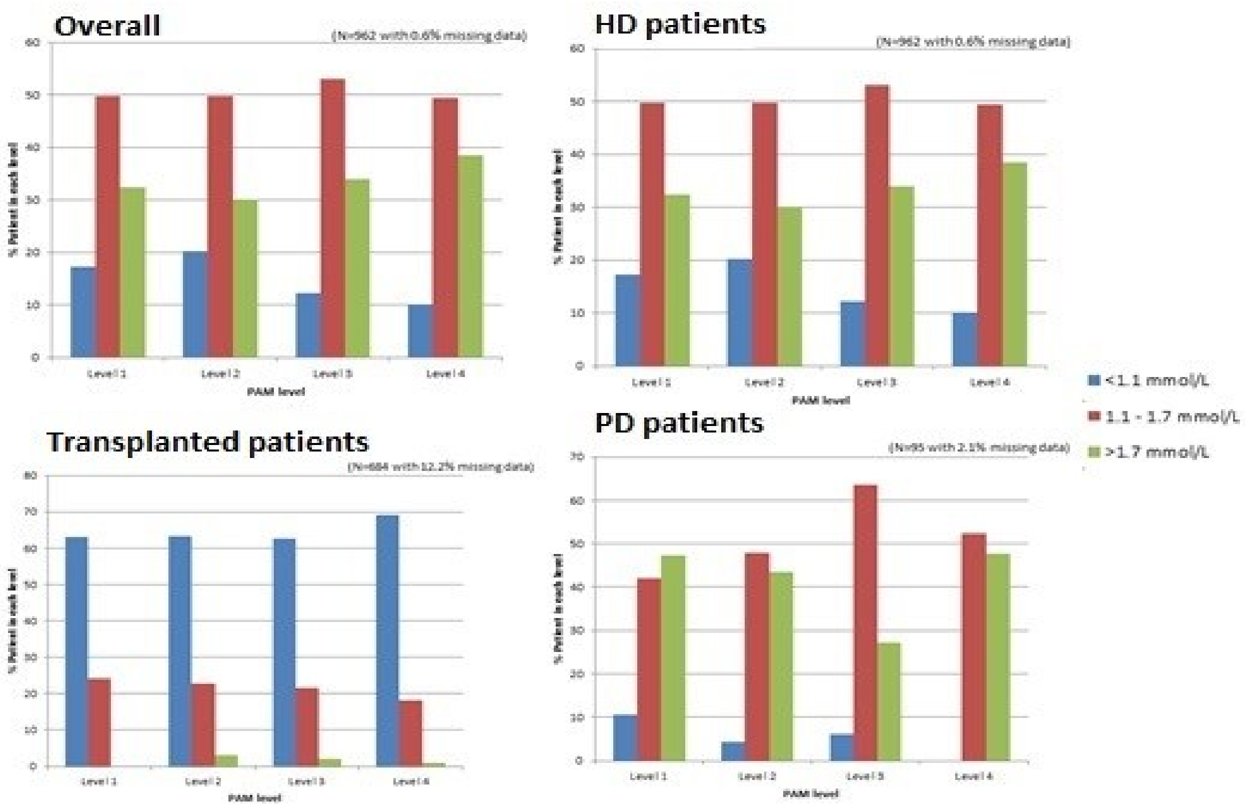

Figure 16: Phosphate by PAM level by modality

Figure 16: Phosphate by PAM level (RA recommendations for phosphate are: Patients on dialysis is 1.1 – 1.7 mmol/L)

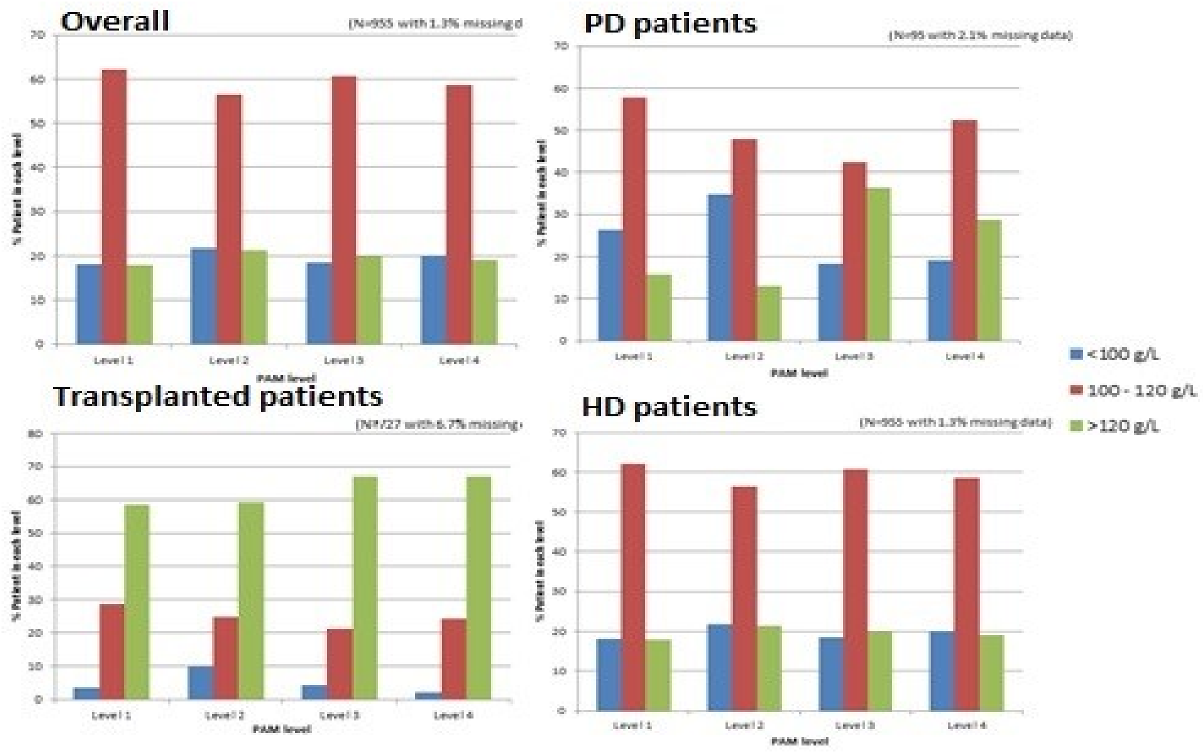

Figure 17: Haemoglobin by PAM level by modality

Figure17: Haemoglobin by PAM level (RA recommendations for haemoglobin are: Aim of treatment is to maintain levels in range of 100-120g/L (i.e. not to normalise the haemoglobin level).

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