

## Transforming Participation in Chronic Kidney Disease

**Aim:** To empower people to take greater control of their health and wellbeing in partnership, leading to better outcomes

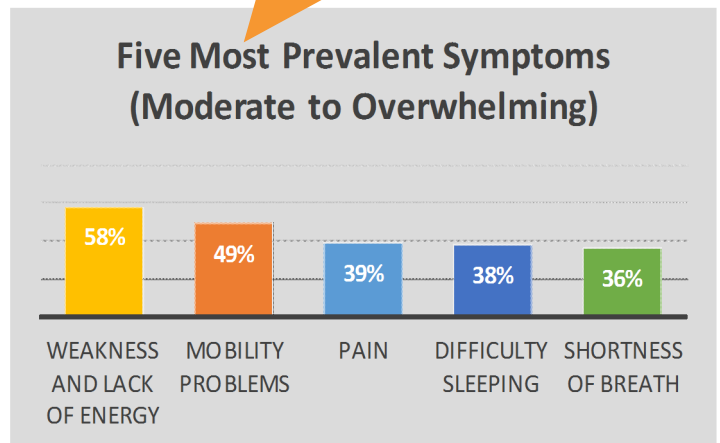
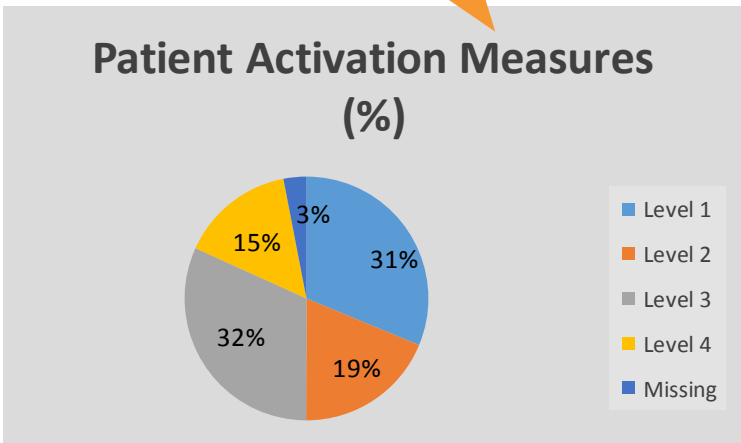
An activated person is one who has been supported to develop the knowledge, skills and confidence to make informed choices about their health care, and who uses services appropriately to support these choices

**The Problem:** Between 25 and 40 per cent of the population have low levels of activation

(Hibbard and Cunningham 2008)

**Data from the UKRR reflects a similar picture...**

**Data from the UKRR also indicates that patients suffer from a symptom burden that has the potential to impact on quality of life and activation...**



**Measuring patients' activation levels** means clinicians can identify those who may need additional support and target it appropriately. The score provides a guidance on the type and amount of support that is likely to be helpful to the patient...

### A Developmental Scale of Patient Activation:

The PAM is calculated as a score which corresponds to a PAM level:

**Level 1**  
**Disengaged and overwhelmed.**  
 Their perspective: my doctor is in charge of my health.

**Level 2**  
**Becoming aware but still struggling.**  
 Their perspective: I could be doing more.

**Level 3**  
**Taking action.**  
 Their perspective: I'm part of my health care team.

**Level 4**  
**Maintaining behaviours and pushing further.**  
 Their perspective: I'm my own advocate.



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The following is a recommended intervention identified by the TP-CKD programme for implementation with both staff and patients, to test the following question:

**“Can the use of intervention tools help to improve the knowledge, skills and confidence of patients with kidney disease to enable fuller participation in the management of their own health?”**

To explore other interventions identified by the programme, visit our Interventions Toolkit at:

[www.thinkkidneys.nhs.uk/ckd/resources/](http://www.thinkkidneys.nhs.uk/ckd/resources/)

## Patient View

## Patient view

**Patient View** is a secure website that gives patients on-line access to details about their kidney care. It shows a person’s latest blood test results, online information about kidney conditions and treatment, and links to other helpful websites. A list of the tablets and medicines, plus an individual’s status on the transplant list is available in some Trusts. Patients can also enter information such as blood pressure readings or blood glucose results.

Units involved in the **TP-CKD Programme** have access to their **Patient Activation Measure and Patient Reported Outcome Measurement** readings.

### What are the benefits?

During 2011, 250 patients were asked for their opinions on using Patient View (NHS Kidney Care 2012) and they stated that Patient View gave them:

- A better understanding of their kidney disease
- More control of their medical care
- More involvement in decisions about their care
- "Peace of mind" about their treatment

Some patients said they found it helpful to share their login details with staff from other renal units when they went on holiday.

**"I now feel that I'm far more in control and I'm now able to see things a lot more clearly than I did before"**

**"I might ring the dietician up and have a conversation about my blood results. I probably wouldn't have done that before I used Patient View"**

### How can it be used?

#### For patients

- Patients who want access to Patient View should ask their health care professional to help provide a login and password.
- This allows patients to login to the site to access records.

#### For staff

- Ensure that the process you have in place for patients to access Patient View is as patient friendly as possible.
- Training and support may be necessary. Consider identifying a dedicated "Patient View Champion" responsible for informing and training patients.