

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)

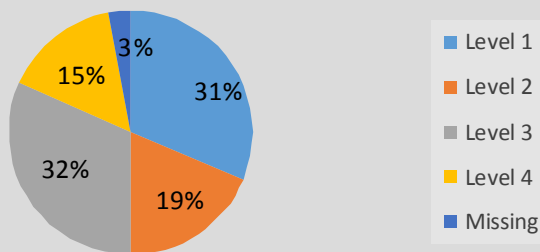
Data from the UKRR reflects a similar picture...



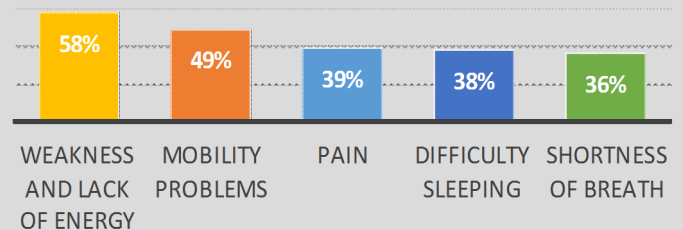
I'm a little overwhelmed, guys.

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...

Patient Activation Measures (%)



Five Most Prevalent Symptoms (Moderate to Overwhelming)



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.

Increasing Level of Activation

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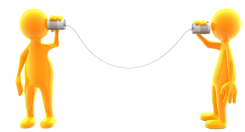


The following is a recommended intervention identified by the TP-CKD programme for implementation with both staff and patients, to test the following question:

“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/



Effective Communication

Effective communication between the patient and healthcare team is a key skill in person-centred care to support patients to gain knowledge, skills and confidence. **Effective communication** between individuals involves more than just information exchange but includes non-verbal communication, listening, explanation, questioning, negotiation, reinforcement, persuasion, reflecting, opening and closing and self-disclosure (Hargie 2006). It also requires skills to exchange information, feelings and meaning verbally and non-verbally.

What are the benefits?

- Helps build partnerships between patients and health professionals and supports a clear understanding of patient’s concerns and worries
- Listening skills are an important part of good communication; being an “active” listener helps avoid misunderstandings. Good listening skills enable health professionals to understand deeper emotional issues affecting patients and contextualise management
- Good writing skills are an essential part of good communication. A patient’s level of understanding of written information can influence outcomes such as medication adherence or health behaviour change

How can it be used?

For patients

- Supported to gain knowledge skills and confidence to self-manage their condition
- To identify and address issues that impact upon their everyday life beyond clinical outcomes
- To explain and clearly identify the reasons for making decisions about treatment and options based on the values and circumstances important to them
- To help build a relationship of equality with clinical teams where the experience and expertise of the patient matters

For staff

Effective communication helps the healthcare professional focus on the whole person. This includes sharing information and decisions and being sensitive to patient needs.

- Active and attentive listening
- Understanding patient/family problems and working together to find manageable solutions
- Use of open questions where possible to elicit patient thoughts and ideas. Use closed questions in information giving
- For written communication, use clear wording in plain English and explain medical terminology in lay terms
- Involve patients and explain record keeping
- Learn and understand the barriers to communication